Elder Planning Counselor Designation Program

Desk Reference Module 2 – Social & Psychological Issues

Contents at a Glance

This page intentionally left blank

Chapter 1

Long Term Care Issues

---

1 - 1 KEY OBJECTIVE OF THIS CHAPTER

Among elders - particularly those age 80 and older - there is likely no issue more important than long term care. With advanced age comes increased dependence - along with a bevy of questions. Will support be available? Where will it be provided? Who will pay for it? What compromises and accommodations will be necessary?

Increased dependence is a slippery slope that can eventually lead to every elder's nightmare scenario - total dependence. No course on elder planning would be complete without an involved discussion of long-term care issues, options and opportunities.

1 - 1.1 How Will This Objective Be Achieved?

We will take a "soup to nuts" tour of long-term care in Canada. Along the way we will cover such diverse topics as:

- Long term care issues
- Types of services available
- Levels of care
- Care providers
- Care settings
- Costs
- Funding and funding options

1 - 2 INTRODUCTION

After a long and fruitful life of careful saving and investing, we all hope to settle into a well-planned retirement. Our vision may be to spend time with family and friends and visit far-away places.

The last day on the job has finally arrived and everything is in place for a carefree retirement—our investments have performed well, we have life insurance in place, the wills are current, and the house is mortgage-free. The only thing missing may be good health and our ability to live independently.

This century has been one of incredible advances in science and technology. We live in an era of ever increasing public knowledge about proper nutrition and exercise. In many respects, elders have never been more blessed. Two hundred years ago, people considered themselves lucky to live to the age of 35. A century ago, only a small percentage of the population reached what is now considered retirement age.

While there has never been a better time to grow old, longevity does not necessarily produce quality of life. Many elders live almost solely by the grace of modern medicine. They live but are never cured. Their bodies ravaged by illness and infirmity.

Many of us will eventually find ourselves propped up by technology, living in a limbo between life and death. Some of us will require around-the-clock care. We will need intensive support simply to get by: to feed and dress ourselves, to toilet, to transfer - to perform the simple daily functions that most of us take for granted.

1 - 3 ISSUES AND PROBLEMS

Not long ago, providing long term care was a difficult, but relatively straightforward affair. Few people lived to old age. Even fewer were beset by long term, debilitating chronic illness. And when disaster did strike, there were several generations of a large extended family living close at hand - ready and able to provide needed support.

The situation is not nearly so straightforward in modern Canada.

1 - 3.1 The "Silver Tsunami"

Today, a 50-year-old can expect - on average - to live another 30 to 35 years! Modern medicine and healthy lifestyles are combining to blow current survival projections out of the water. In fact, by the time today's 50-year-old reaches age 80, scientific and nutritional advances may offer him or her yet another 10 or 15 years of life. As a result, it should come as no surprise that centenarians are poised to become the fastest growing segment of Canada's population.

Unfortunately, longer lives will not mean an end to the aging process. Science has not conquered that one, yet. The human body still tends to wear out - and with advancing age, we tend to need help.

As people age, the major causes of illness change too. People become frail and diseases that are quite uncommon among younger individuals (e.g., Alzheimer's disease) take hold. Managing many age-related illnesses become difficult to do at home. It can be extremely stressful and physically demanding.

The growth in the size of the population in the very oldest age categories is about to put enormous strain on our social safety net - since the "old old" have greater needs, than younger elders, for such things as social support and health care, especially long-term care. According to the C.D. Howe Institute, as the baby boomers move in masse into their elder years, the cost to the Canadian health care system will be approximately 1/2 trillion dollars between now and mid-century.

1 - 3.2 Changing Family Structures

Women have moved in droves outside the home to the workplace. The income they earn is often far from incidental. It is needed to help support the family.

Soaring divorce rates have merely compounded the problem. Unattached women become not just breadwinners - but the primary breadwinner. And since they may require an even higher income, they often pursue more challenging careers - careers that leave little time or energy for domestic duties.

As a result, women have become increasingly unavailable to care for elderly family members who are in need. Even so, the average woman will still spend 17 years raising children and 18 years taking care of aging family members. More telling still, a Canadian government study has determined that the number one reason for absenteeism in the workplace, for women over age 45, was caring for aging parents.

These changes in family structure and roles have placed enormous strain on many individuals. These changes have also pointed to an increasing need for professional help—and outside help.

1 - 3.3 Institutional Care

Not very long ago, there was a huge social stigma attached to institutional care. Fifty years ago, the proper thing was to care for the elderly either at home or in a hospital. Those who ended up in a nursing home were considered "dumped." It was thought that children who truly loved their parents and grandparents would make sure their remaining years were spent in their own homes or the homes of relatives.

This stigma has been largely removed. Placing an elder in a Long-Term Care Centre is now considered perfectly acceptable. Why?

Part of the answer lies in the quality of care now received. Years ago, there were some excellent facilities, but there were also many that were poorly run. Media attention, negative publicity and government regulations have combined to vastly improve the overall quality of the care provided.

1 - 3.4 The Role of Government

Institutional care in Canada is heavily supported by government subsidies - and Canadians have been accustomed to looking at the government as a "free and readily available" source of health care. But this has changed over the past decade and we can expect even more changes to come.

The graying baby boomers will put an enormous strain on health care costs and their availability. The government will begin to buckle under the pressure. Individuals with the financial ability to pay will, in the future, likely have better access to both home care and long-term care..

Major changes recently enacted in Ontario are indicative of future trends. The Ontario Long-Term Care Homes Act was introduced in 2009, and implementation began in 2010. Under the new act it is significantly more difficult for an elder to gain access to subsidized nursing home care.

Under the act, strict new criteria must be met, before the CCAC (Community Care Access Centre) will refer a person to long-term care. Before the new act, these medical needs did not need to be established.

As a result, long-term care homes across the province are seeing an increase of people with more complex-care needs than a decade ago — including mental-health issues. Other elder applicants, with less severe issues, are simply turned away.

The act has produced two troubling outcomes. Many elders must now fend for themselves. And the complex needs of the residents who do still qualify for subsidized long-term care, are putting additional strain on the system.

1 - 4 LONG-TERM CARE DEFINED

Over the next decade, approximately 47 million baby boomers in North America will be facing the role of caregiver to a parent, relative, or elderly friend—an odyssey that will change many of their lives. At the same time, countless thousands of elders will face the dilemma of caring for a chronically ill spouse.

Long term care includes all the assistance you could possibly need if you ever have a chronic illness or a disability that leaves you unable to care for yourself for a prolonged period.

Individuals can receive long term care at home, in an assisted living facility or in a nursing home. Long term care is assistance with any activities of daily living, which can include bathing, dressing, transferring, eating, and continence. Older people use most long-term care services; however, a younger person who has suffered a serious illness or been in an accident can also use long term care.

Care is not just for elders and it is not just delivered in nursing homes. A wide variety of very different people may require a range of different long-term care services.

Someone recovering from a stroke may simply need in-home help with shopping, cooking, and cleaning. This is the kind of assistance is provided by a lower cost licensed homemaker service. In addition, this kind of assistance may be needed for only a year or two.

After leaving the hospital, someone recovering from surgery may need 24-hour monitoring and other services in a skilled nursing facility.

Yet another patient, suffering from Parkinson's disease may need help with daily living routines, continuous physical therapy and more. This patient might need intermediate care in a nursing home for life.

Meanwhile, an Alzheimer's patient, with only mild symptoms at the onset of the disease, may be manageable at home in the evening and on weekends. However, working family members might need to place this individual in an adult day-care facility during working hours.

A person with a physical illness or disability will often need "hands-on" assistance with the activities of daily living. But a person with a cognitive impairment will usually need supervision or verbal reminders to do everyday activities or, perhaps, in order to keep them from doing harm to themselves or others. The way that long term care is provided will differ with the type and level of care that is needed.

It is also important to note that long term care distinguishes itself from traditional medical care insofar as it is meant to help one live as he or she lives currently - and it may not be designed to help improve or correct a medical problem.

1 - 4.1 Long-Term Care - By the Numbers

When contemplating the future, at some point, most elders will ask themselves the following question: what are the chances that I will need long-term care?

In truth the answer to this question is simply this: an elder’s chances of needing long term care are either 0% (he will never need it) or 100% (he will need it). It is a lot like the lottery, and it is a lottery the elder does not want to win.

The bad news is that the odds of winning this lottery are pretty good!

According to a recent study produced by leading long-term care insurance actuaries (they are the folks who price long-term care insurance), the lifetime chance someone age 60 will need long term care before they die is 50%. So, 50% will need long term care and 50% will not.

A 50-50 likelihood that an elder will need long term care is extremely high (which helps to explain why long-term care insurance is costly).

Of the 50% of elders who will need long term care, almost all of them will - at some point - need home care. For elders between the ages of 75 and 85 - who are still in their homes - in-home health care will become a way of life, requiring an average 70 visits a year from an in-home health service provider.

And of the 50% of elders who will need long term care about 80% will eventually need nursing home care. Of this group:

- 23% will spend up to three months in a long-term care facility
- 21% will spend three to 12 months in a long-term care facility
- 35% will spend one to five years in a long-term care facility
- 21% will spend more than five years in a long-term care facility of some kind

According to Statistics Canada, the chances that an elder will require long term care ratchet up dramatically with age. As already noted about 50% (or one in two) of Canadian elders age 60 will eventually need long term care. Here are the odds of needing care at various ages:

- At age 55, the odds are 1 in 10
- At age 65, the odds are 3 in 10
- At age 75, the odds are 5 in 10
- Past age 75, the odds are 7 in 10

The above statistics focus exclusively on individual elders. The situation for elder couples is somewhat bleaker. A recent study by Munich Re looked at the odds of a Canadian couple, both age 60, needing long term care. The chances that one of them will at some point need long term care are better than 80%.

In short, for the average elder couple – it is almost a given that at least one of them will need some long-term care at some point.

1 - 4.2 The Impact of Family History

The chances of an individual requiring long term care increase if certain chronic conditions runs in the family. Arthritis and heart disease often run in families - and they are also the two most common conditions that create a need for long term care.

Anyone suffering from more than one chronic condition is also at greater risk.

While Canadians are becoming more educated on the possibilities of future care in a nursing home, many still believe it will happen to that mysterious "other person." The truth is it can happen to anyone, regardless of gender, creed, race, financial standing, or family structure. Although it is often made out to be a social issue, the need for nursing home care is a health issue.

1 - 5 THE CONTINUING CARE CONTINUUM

Canada’s health programs are primarily under provincial jurisdiction and as such, programs may vary slightly from province to province. When it comes to caregiving, the goal is to help people to live if possible, in their home with assistance from within the community and when this is no longer viable, helping them find facility-based care. This is accomplished through either a single-entry point or through co-ordinated access to a range of health services and social services.

The term, *continuing care*, is indicative of the fact that health care delivery is a continuum which includes many different service components delivered over an extended period.

The process may begin when an elder is being released from hospital following surgery for a life-threatening condition such as cancer. Prior to release, the physician may arrange for home care services.

Alternatively, the process may begin when an elder's visit to the family physician reveals they are experiencing difficulties in cognition or caring for themselves, as may be the case with Alzheimer’s. In either event, a case manager should be appointed and he should meet with the individual and family to complete an assessment, and to arrange for service delivery within the elder’s home.

Once a case manager is in the picture, ongoing reviews should be conducted periodically, and the care plan should be adjusted, as necessary.

Ultimately, when the individual can no longer be cared for within the home and community, the case manager should recommend relocation to a long-term care facility.

In some provinces, the role of the case manager ends when an elder is admitted to a long term care facility, while in other provinces their role continues.

An alternate to the use of a long term care facility is a retirement home with assisted living - it is ideal for elders who can no longer manage in their own homes, but who do not yet require the services of a long term care centre. Facilities of this nature are outside of the continuing care system, and access to them is obtained by directly contacting the facility itself.

Privately run nursing homes also operate outside of the system since they do not receive any form of government subsidization.

1 – 5.1 Problems with the Continuing Care Continuum

As noted above, Long-term care should be a continuum that includes various degrees of support through informal care, home care and institutional care. Unfortunately, the current system does not reflect this. Canadians currently have a very plain system marked by a lack of coordination between institutional structures. As a result, particularly from a patient perspective, the system is complex to navigate. This complexity increases stress on the individual and those that act of behalf of the patient to help with care needs (e.g., informal caregivers).

The lack of coordination across various institutional supports also leads to significant inefficiencies in the system as different types of care are provided without an overall coordinated approach. As a result, resources are not optimally allocated to where they are needed most, and duplication can occur.

Ideally the system would find ways to seamlessly transition individuals along the continuum as their needs change. One model that shows promise in this regard is all-in-one or holistic organizations that provide the entire continuum of services to individuals. International experience, such as in New Zealand and Australia, has shown that care provided across the continuum can be extremely successful both from a cost and quality of life perspective.

One area of stress for Canadians currently is how best to navigate within the current system. The creation of a single point of contact for the long-term care system would be very beneficial. In addition, the creation of a larger coordinator role (beyond the current case manager) or patient advocate who would guide patients through the continuum of care (both public and private) would help to ensure seamless transition along the continuum.

1 – 5.2 Costs

The cost of long-term care for an elder is initially less within their home and the community. But as their condition worsens, the cost of care becomes less expensive in a long-term care facility, than in the community.

The cost per day of providing support varies dramatically depending on the type of setting. For example, the North East Ontario Local Health Integration Network (LHIN) found that the average daily cost of a hospital bed, long-term care bed and home care are $842, $126 and $42, respectively.

Given the difference in costs across long-term care settings, there are significant cost savings, as well as likely improved health care outcomes, to be realized if patients are treated in the most appropriate and lowest cost settings possible. It would be hugely beneficial to implement fundamental structural reforms that would move individuals from high cost hospitals into lower cost long-term care settings as well as allowing individuals to stay in their homes longer.

It has been estimated that thirty-seven per cent of elders on the Toronto Central long-term care waiting list in 2012 could have been supported safely and cost-effectively if they were to receive care in their own homes.

Reviews of the current system have also determined that there are approximately 7,550 acute care beds in Canada that are taken up by individuals who should be in long-term care or in rehabilitation. This represents about 7 per cent of all hospital beds in Canada. Not only are these individuals receiving a sub-optimal level of patient care, but the costs associated with this care are significantly more expensive than it needs to be. Shifting these patients to a more appropriate long-term care setting would free up capacity for those requiring a more intensive level of care.

If systemic reform were able to transition all those in a hospital setting to a more appropriate long-term care institution, the savings to the system would be in the billions of dollars. In addition, if we could move even 20 per cent of the resulting individuals out of long-term care institutions and provide them with support in the home, the savings would also be in the billions.

Embarking on fundamental structural reform, therefore, will not only improve patient care, but will provide meaningful fiscal capacity to governments.

1 – 5.3 Capacity Issues

Long-term care facilities are dealing with capacity challenges. There are currently about 300,000 people residing in long-term care facilities in Canada. We already know that there are capacity issues given the number of Canadians in hospitals waiting for appropriate long-term care beds to become available. The number of seniors receiving long term care in a hospital setting almost doubled during the first decade of the 21st century. As a result, the overall wait times for individuals seeking placement in long-term care facilities has increased dramatically. For example, in 2016/2017, the median wait time for placement in Ontario was over 90 days for elders currently being cared for in hospitals and 150 days for elders in the community.

While there is a problem today, given the age demographics, the problem will only grow. If we assume residency rates of the present population, it can be predicted that Canada will need over 800,000 long-term care beds by the year 2047 – over 2.5 times what we have now. Even if we assume a much greater use of home care for Canadians, there will be a significant increase in the number of facilities required for the long-term care needs of Canadians.

Indeed, based on the average size of current long- term care facilities in Canada, to meet this future demand Canada will need almost 6,000 addition long-term care facilities to be built over the next 35 years. This works out to almost 170 new facilities per year over this period.

Given the magnitude of the issue, as well as the current fiscal challenges facing governments, governments will not be able to provide all the funding for new facilities. It is critical, therefore, that both the private and public sectors play a role in meeting this need.

1 – 5.4 Manpower Issues

There is a shortage of health care practitioners - physicians, nurses, physiotherapists, nutritionists, chiropractors, etc. - that work in the area of geriatrics. For example, there are currently about 200 geriatric medicine specialists practicing in Canada. In contrast, Sweden with a population less than one-third the size of Canada's has 500 geriatricians.

The shortage is set to intensify over the coming years. The number of internal medicine residents entering geriatric medicine programs has decreased dramatically over the last 10 years. The Canadian Geriatric Society reports that in 2007 there were only five trainees in English-speaking programs for the entire country. Similarly, care of the elderly family medicine training programs has many vacancies.

To fully address Canada’s serious shortage of geriatrics health professionals, action is required to attract more practitioners, including younger practitioners, to enter the field of geriatric medicine. This plan must be supported by federal and provincial stakeholders and it will require resources to ensure successful implementation.

In addition to the physician shortage, there is a looming nursing shortage, particularly in the geriatric specialty. For example, the number of registered nurses that work within the area of geriatrics/long-term care decreased by 3.5 per cent between 2006 and 2010. As a result, as the need for nurses increases, including in long-term care, the pool of available nurses has been on the decline. This has been the result of an aging workforce, poor working conditions and heavy workloads. This serves as a disincentive for the retention of nurses.

The nursing profession has also experienced inequities in salary and other working conditions between the hospital sector and the home health care and long-term care sectors. When positions come available in the hospital sector, nurses from home care and long-term care are attracted to move because of compensation disparities, including access to benefits like pensions. This contributes to gaps in continuity of care and reduced morale.

1 – 6 TYPES OF CARE

1 – 6.1 Care Level Classifications

Some provinces use a consistent classification system to assess the care level required regardless of whether the care is delivered in the home or in a facility.

It is the case manager who performs this role, and the care level assigned reflects psychosocial and physical functional ability. Care level classifications help determine the type of facility appropriate for care and they are used to plan the future allocation of resources.

There are five different levels of care:

1. **Personal Care**

People who are independently mobile, with or without mechanical aids, and who require minimal - non-professional - supervision and assistance with the activities of daily living need Personal Care.

2. **Intermediate Care 1**

A person who is independently mobile, with or without mechanical aids, and who requires moderate - professional - care and assistance with the activities of daily living needs Intermediate Care 1.

3. **Intermediate Care 2**

The basic characteristics of Intermediate Care 2 are the same as for Intermediate Care 1. The only difference is that Intermediate Care 2 requires either heavier care and or supervision requiring additional care time.

4. **Intermediate Care 3**

Intermediate Care 3 is required under two scenarios. It may be needed for persons requiring a heavier level of care, involving considerably more care time than at the Intermediate Care Level 2, but who are not yet eligible for Extended Care.

It may also be required in the case of psychogeriatric individuals who have severe behavioral problems on a continuing basis.

5. Extended Care

Extended Care is reserved for individuals with a severe chronic disability that - in most cases - has produced a functional deficit that requires 24 hours a day professional nursing services and continuing medical supervision but does not require all the resources of an acute care hospital.

Most people at this level of care have limited potential for rehabilitation and often require institutional care on a permanent basis.

1 – 6.2 Trends/Changes in the Type of Health Care Needed

The Canadian health care system has faced challenges in recent years due to several factors, including changes in the way services are delivered, fiscal constraints, the aging of the baby boom generation and the high cost of new technology. These factors are expected to continue in the future.

Since publicly funded health care began in Canada, health care services and the way they are delivered have changed - from a reliance on hospitals and doctors to alternative care delivery in clinics, primary health care centres, community health centres and home care; treatment using medical equipment and drugs; and a greater emphasis on public health and health promotion.

Medical advances have led to more procedures being done on an out-patient basis, and to a rise in the number of day surgeries. Over the past several decades, the number of nights Canadians spent in acute-care hospitals on a per capita basis has declined, while post-acute and alternative services provided in the home and community have grown.

Beginning in the mid-1990s, most provinces and territories worked to control costs and improve delivery by decentralizing decision-making on health care delivery to the regional or local board level.

Such regional health authorities are managed by appointed members who oversee hospitals, long-term care facilities, home care and public health services in their area. However, in recent years, some provinces have moved away from a decentralized model of health care delivery in favour of consolidating the number of health authorities and centralizing decision-making structures.

As our population ages during the next several decades, the need for more intensive care will trend upwards. Less Personal Care and Intermediate Care 1 will be needed - but the need for Intermediate Care 2 and 3 and Extended Care will increase.

1 – 6.3 Long-Term Care "Timing"

Long term care may be needed in one of two ways:

Scheduled

Scheduled activities are those that can be performed on a regular schedule at times of the day. For example, people may lose the ability to dress themselves. If scheduled visits are arranged to give assistance with that single ADL, these individuals can function adequately during the remainder of the day with a minimum support system at home.

On-demand

On-demand activities are those that must be taken care of on demand. As a chronic condition progresses, a person will need help in performing activities of daily living when they require assistance at *any* time during the day. Scheduled visits will not be enough to provide adequate care. The individual may require long term care in a setting other than the home because they will need help throughout the day.

1 – 6.4 Types of LTC Services

There are many types of long-term care services available. A variety of them are covered in the material which follows.

Physician Services

Physician Services are medically oriented services provided by licensed physicians - including the development and approval of a plan of care.

Nursing Services

Nursing Services are medically oriented services by licensed professionals - including medicating and monitoring medical equipment.

Therapy Services

Therapy Services are rehabilitative services including physical, speech, and occupational therapy.

Meal Delivery

Regular, nutritionally balanced meals are delivered to the home of an individual who is unable to prepare meals on their own.

Congregate Meals

Congregate meals are regular, nutritionally balanced meals that are provided - at a central site - for individuals who **are** unable to prepare meals on their own.

Homemaker Services

Homemaker Services include assistance with basic household tasks such as preparing meals, doing laundry, and other incidental household activities.

Chore Services

Chore Services include assistance with light work such as simple household repairs, taking out the garbage, and other related tasks.

Personal Care Services

Custodial care, sometimes called personal care, is care that is mainly for meeting daily living requirements, such as bathing, dressing, eating, or taking oral medications. Persons without medical training or skills may provide custodial care.

This level of care is intended to maintain and support an existing level of health or to preserve the patient from further decline. A case manager, in consultation with the physician, must recommend this type of care. It is not recommended simply for the convenience of the elder or the elder's family.

Home Health Aide or Personal Care Attendant services

These services assist functionally impaired individuals with personal care needs such as bathing, dressing, and other activities of daily living.

Social/Community Care

Community care may be provided in a variety of ways. Adult Day Care centres, for example, provide a variety of health, social, and related support services during the day in a protective setting for functionally impaired adults. Elder Centres meanwhile provide social and support services - including special programs for elders with impairments.

Transportation Services

Transportation Services includes transportation for those who have special needs as well as those without other sources of transportation.

Respite Care

Respite care provides a break in routine for those who give and receive care, offering companionship and monitoring for short periods on a regular or occasional basis.

Respite care is short-term care that is required in order to maintain the health or safety of the patient and to give temporary relief to the primary caretaker from his or her care-taking duties.

This is very important because a caregiver needs time for himself or herself if they are to remain physically able to continue giving care.

Hospice Care

Hospice Care provides palliative care by alleviating the physical, emotional, social, and spiritual discomforts of an individual who is experiencing the last phases of life due to the existence of a terminal disease.

Equipment and Supplies Support

Home modifications and equipment includes hospital beds, wheelchairs, walkers, support railings, access ramps, emergency response systems, and home testing or monitoring equipment.

Supplies include oxygen, incontinence, and other supplies.

Medical Alert Systems

These systems provide emergency notification to medical services in the event of an illness or injury.

Other Services

In addition to the above services, basic health care and nutrition services may also be supplied.

1 – 6.5 Service Providers

Long term care services may be provided by informal caregivers such as family members or friends, as well as by formal care givers who are specially trained and/or licensed professionals.

The key distinction between formal and informal care is the financial relationship of the caregiver to the patient—paid caregivers are classified as formal care, while unpaid caregivers are classified as informal care.

A. Non-Medical Personnel

Non-medical personnel provide a wide variety of services based on the needs of the individual. Their service can include:

- Assistance with personal care such as bathing, grooming, eating, or toileting
- Assistance with movement or exercise

- Simple health tasks such as taking temperature and blood pressure and assisting with self-administered medications
- General homemaking such as grocery shopping, meal preparation, light housekeeping, and laundry

B. Skilled Medical Personnel

Skilled medical personnel include nurses, therapists, and physicians who provide a wide variety of services based on the needs of the individual. Their service includes:

- Monitoring diet and nutrition
- Monitoring patient nursing needs, including giving injections and diagnosing routine medical problems
- Planning and implementing a program of rehabilitative therapy

1 – 6.6 The Role of the Case Manager

Government and private case managers get referrals from many sources - among them:

- Family Members
- Hospital social workers
- Outreach programs
- Self-referrals
- Home health agencies

After they have received a referral, the first order of business for the case manager is to do a detailed assessment of the individual involved. The case manager looks at many factors in evaluating what is the most appropriate care. Some of these factors are:

- The elder's ability to live alone despite a medical or a physical limitation
- Whether they require assistance in taking medication
- The need for around-the-clock supervision
- The need for treating a chronic condition that does not require hospitalization but affects the elder's day-to-day functioning
- Whether the elder requires assistance with the activities of daily living

After completing this assessment, the case manager will look at such related issues as:

- Eligibility for services
- Co-ordination of services
- Connecting clients with supplementary and community resources

1 - 7 ACTIVITIES OF DAILY LIVING

Activities of Daily Living (ADLs) are those activities which an individual must perform every day to continue living independently.

When assessing an individual's ADLs, the medical profession looks at a couple of factors:

- The number of activities that an individual can do
- The degree of independence in performing the activities

The older we grow the more likely we will need some sort of assistance with the activities of daily living. This is not necessarily due to illness or injury - often it is simply a function of old age. In many cases a combination of illness and old age come into play.

While there are different definitions of the activities of daily living, they commonly include some variation of the following:

- Bathing and Eating
- Transferring and Dressing
- Toileting and continence
- General mobility

While difficulties with respect to one ADL are not a good indication that the individual will end up in a nursing home … a combination of them is a reliable indicator.

A person with a physical illness or disability will often need *hands-on* assistance with ADLs. A person with a cognitive impairment will usually need supervision or verbal reminders. It is important to remember that these cognitive impairments are not measured by ADL limitations.

1 – 7.1 Instrumental Activities of Daily Living (IADLs)

Instrumental Activities of Daily Living are those activities that an individual wants to - rather than must - perform on a regular basis. The difference between ADLs and IADLs comes down to "need to do" versus "want to do."

Among the IADLs:

- Traveling outside of the home
- Keeping track of household finances
- Meal preparation
- Housework or outside chores

- Telephone use
- Taking oral medications appropriately

The following form can be used as a guideline to help measure Instrumental Activities of Daily Living.

Table 1 - 1 Sample Form to Measure Instrumental Activities of Daily Living

Abbreviations: I – independent; A – assistance; D – dependent
1. Telephone: **I:** Able to look up numbers, dial, receive, and make calls without help. **A:** Able to answer the phone or dial operator in an emergency but needs a special phone or assistance in getting the correct number for dialling. **D:** Unable to use the telephone.
2. Travelling: **I:** Able to drive own car or travel alone by bus or taxi. **A:** Able to travel, but not alone. **D:** Unable to travel.
3. Shopping: **I:** Able to take care of all shopping with transportation provided. **A:** Able to shop, but not alone. **D**: Unable to shop.
4. Preparing meals: **I:** Able to plan and cook full meals. **A:** Able to prepare light foods but unable to cook full meals alone. **D:** Unable to prepare any meals.
5. Housework: **I:** Able to do heavy housework (i.e. Scrub floors). **A:** Able to do light housework but needs help with heavy tasks. **D:** Unable to do any housework.

6. Medications: **I:** Able to take medications in the right dose at the right time. **A:** Able to take medications but needs reminding or someone to prepare them ~~it~~. **D:** Unable to take medications.
7. Money: **I:** Able to manage buying needs, write cheques, pay bills. **A:** Able to manage daily buying needs but needs help managing cheque book and paying bills. **D:** Unable to manage money.

1 - 8 TYPES OF LONG-TERM CARE

Long term care is provided in the home, community, and various institutional settings.

1 – 8.1 Home Delivered Care

This care encompasses a multitude of medical and non-medical services for a partially or fully dependent person.

The purpose of providing care in the home is to enable the individual to remain as independent as possible, maintaining their dignity and minimizing the costs of care. Services provided in the home include nursing services, therapy services, home health services, homemaker services, chore services, respite care, hospice care, and home delivered meals.

In 2012 almost one million Canadians aged 65 or older reported that they had received formal and/or informal home care in the past 12 months. However, it is likely that the prevalence of the use of home care is greater. Some informal care, from a spouse, for instance, may not have been reported, since it may be perceived as part of usual support provided to family members.

In Canada, a larger percentage of senior women receive home care versus their male counterparts (30% versus 18%). For both sexes, the percentage who receive home care rises with age from 12% of men and 18% of women aged 65 to 74, to 44% of men and 59% of women aged 85 or older.

Seniors living alone are more likely than those living with others to have received home care. As well, a higher percentage of seniors who reported some form of social assistance as their main income source receive home care, compared with those who reported another main source of income. Living alone and lower income are associated with higher rates of home care use.

Seniors with limited functioning are more likely than those in better health to receive home care. Half of severely disabled seniors receive home care, compared with 12% of those who have no or mild disability. A relatively high percentage of individuals with physical limitations receive assistance with personal care activities such as bathing or toileting, compared with people who did not have these limitations.

The prevalence of home care use (formal and/or informal) varies across the country. Reported use of home care is lower in Newfoundland and Labrador (18%) and Quebec (22%), and higher in New Brunswick (29%), Ontario (27%), and Manitoba (29%), when each province was compared with the rest of Canada. Estimates for the remaining provinces fell in between the extremes.

More than half (53%) of seniors who received home care indicated that it had been provided exclusively by informal sources such as family, friends and neighbours. Another 18% received only formal home care from paid employees and unpaid volunteers. The remaining 29% reported mixed sources of care, underscoring the complementary relationship between the informal and formal care networks.

The sources of care differed somewhat by the type of care provided, and for nearly all types, the informal network generally predominated. The exception was medical care, with equal shares reported to be coming from formal and informal providers, and a smaller share from mixed sources.

1 – 8.2 Community Delivered Care

This care encompasses a multitude of medical and non-medical services for a partially or fully dependent person. The purpose of providing care in the community is to serve many people at a minimal cost, offering an opportunity for individuals to remain as independent as possible. Services provided in the community include adult day care, hospice care, therapy services, nursing services, transportation, and congregate meals. This care could be skilled, intermediate, or custodial care and personal care.

1 – 8.3 Adult Day Care

This type of care is a program of community based social and health-related services provided during the day in a community group setting for the purpose of supporting frail, impaired persons who could benefit from care in a group setting away from their home. This may be a greater benefit for the home caregiver, which is often a spouse or child. With the patient gone for the day, the caregiver can relax; catch up on sleep, or simply run needed errands. It also is an alternative that can enable a caregiver to continue working outside the home, while providing care for an aging parent.

1 – 8.4 Chronic Care

Chronic care, sometimes called maintenance care, is a type of care that is necessary to support an existing level of health. It is intended to preserve that level of health from further failure or decline.

Because it is caused by a chronic health condition, the care is usually necessary for a long, drawn out or lingering disease or condition and there is little chance of a complete recovery. Sometimes the condition does improve, but it is unusual for it to completely vanish. This type of care may be provided in an institution, the patient's home, or in a community setting and may be skilled, intermediate, or custodial, depending upon the person's personal health care needs.

1 – 8.5 Convalescent Care or Rehabilitative Care

This type of care is considered non-acute care. A doctor must prescribe it and the care is received during the period of recovery from an illness or injury when improvement is anticipated. The care received may be skilled, intermediate, or custodial. It may also be a mix of the three levels of care. The care may be received in an institution, at home, or in a community setting.

1 – 8.6 Hospital Care

Elders are generally far more likely than those in younger age groups to be hospitalized - three times more likely in fact.

According to the Canadian Institute for Health Information, in 2011, seniors were responsible for 47.1% of all hospital admissions and they consumed 40% of all hospital services.

Repeat admissions were also more common among seniors than younger people. And once elders are in hospital, they typically spend more time there than do younger people.

The average length of a hospital stay for seniors 65+ is roughly 10 days. For seniors 75+ it is 22 days. Both numbers are significantly higher than the average stay for the overall population (i.e., 7 days) in 2016.

1 - 9 LONG-TERM CARE CENTRES

A Long-Term Care Centre, sometimes referred to as a Nursing Home, is an entity that provides skilled nursing care and rehabilitation services to people with illnesses, injuries, or functional disabilities. Most facilities serve the elderly. However, some facilities provide services to younger individuals with special needs, such as the developmentally disabled, mentally ill, and those requiring drug and alcohol rehabilitation. Long term Care Centres are generally stand-alone facilities, but some are operated within a hospital or retirement community.

1 - 9.1 Common Names

Long Term Care Centres, Nursing Homes, Continuing Care and Special Care Facilities, Residential Care Facilities, Complex Care Facilities, Auxiliary Hospitals, Special Care Homes, Personal Care Homes, Homes for the Aged, Manors and Government Manors.

1 - 9.2 Target Audience/Residential Profile

These facilities are designed for convalescent elders or those with long-term illnesses or disabilities who are not able to care for themselves and have numerous health care requirements.

The typical nursing home resident in Canada is age 85 or older and she faces many challenges including multiple chronic diseases along with problems with mobility, memory and incontinence. Many residents are completely dependent on staff for the most basic activities of daily living such as toileting and eating.

A 2012 assessment of the profile of the Canadian long-term care residential population paints a vivid picture of their characteristics and needs. Of the roughly 300,000 Canadians currently in long term care facilities only one in every 15 was under the age of 65 and nearly half were very old (age 85 or older). The average age was 82. Sixty nine percent of residents are female.

Of these residents, the most common affliction was bladder incontinence. Seventy percent of Canadian long-term care residents suffer from bladder incontinence – an important health and quality of life issue. Dementia, including Alzheimer’s disease, was the next most common health care issue with three in five residents of Canadian long-term care facilities having this diagnosis on their health record.

More than half (56%) of the residents of long-term care facilities are afflicted with musculoskeletal conditions (such as arthritis, fractures and missing limbs). As well, nearly half (49%) of the residents of Canadian long-term care facilities have problems with bowel incontinence.

Many of the current residents of Canadian long-term care facilities are also impacted by social and psychological issues. Close to half have limited, or no, outside social engagement and almost a third have signs of clinical depression. A quarter of long-term care residents in Canada have diabetes.

Interestingly, the type of impairment experienced by nursing home residents varies significantly across the country. Residents with a moderate to severe cognitive impairment are much more common in Manitoba than elsewhere, while residents with a moderate to severe physical impairment are far more common in Newfoundland.

1 - 9.3 Services Available

The level of care provided by Long Term Care Centres has increased significantly over the past decade. Many homes now provide much of the nursing care that was previously provided in a hospital setting.

The Long-Term Care Centres provide twenty-four-hour skilled nursing, assistance with activities of daily living, health services, and several activities.

Their goal is to integrate custodial care with nursing, psychosocial, and rehabilitative services on a continual basis.

These facilities are designed to care for elders who have a variety of chronic conditions and disabilities. Some facilities offer specialized programs for people suffering from advanced stages of Alzheimer's disease or other dementia.

1 - 9.4 Housing Arrangements

These Long-Term Care facilities vary from institutional or hospital-like settings to settings that are more home-like. Skilled Care facilities may be stand-alone, integrated or near Assisted Living facilities, or may exist as a component of Continuing Care Retirement Communities. The living space may include private or semiprivate rooms shared with a roommate. Strict safety regulations are adhered to within these facilities to accommodate the physical and mental disabilities of their residents.

1 - 9.5 Payment Methods

In most provinces, approximately two thirds of the overall Long-Term Care Centre's operating costs (including mortgage payments) are provided by government in the form of resident subsidies. Most residents require government subsidy for nursing home services.

Many residents pay for their share of the costs out of their own private funds, but some have assistance from Long Term Care insurance policies. Still others may receive help with costs from federal and provincial programs when their finances are depleted.

1 - 9.6 Subsidization

The cost of residing in a Long-Term Care facility is made up of 2 components – the cost of health care and the room-and-board charge.

In most provinces the cost of the health care component is paid for by the provincial government, so the fee charged to the elder represents the cost of room and board only. Even with this "cost sharing," in 2017, long term care facilities usually charged in the range of $900 to over $3,000 for room and board. If the elder cannot afford to pay, a further subsidy may be authorized by using an income test.

In provinces that do not cover the health care component of LTC, monthly charges can exceed $6,000. Both income and asset testing are used by these provinces to determine the cost of facility care. Elders who have income and assets valued higher than the threshold amounts are required to pay some or all the full cost of facility care.

If more specialized care and assistance is required, then Home Care is available at an additional cost and can add up to between $35,000 and $60,000 per year depending on the type of care required.

No one is denied access to a Long-Term Care centre for financial reasons, so the question is how long an individual must wait for a vacant bed. Government subsidies only provide access to ward level accommodation and it is at this level where the wait is the longest.

This can mean a long wait for access. An elder can indicate their preference for a facility but if they have been designated as "high priority" and refuse the first bed that becomes available; their name may be removed from the priority list. Beds are assigned within regions and only across regions if the elder gives permission to receive a bed assignment faster.

When a family member is acting for an elder, he or she must provide a copy of a Power of Attorney. Despite this, it is a wise practice to always include the elder in any discussions and decisions.

1 - 10 THE COST OF LONG-TERM CARE

As Canada's population ages, a growing number of frail seniors will require long-term care services to help them perform daily activities such as eating, dressing or bathing. Ensuring that adequate care is accessible to every Canadian who needs it should be a national priority. But who should foot the bill?

The cost of long-term care services can be very high: 24/7 assistance in an institution costs around $60,000+ per person per year with heavy specialized care. At present, the financing of long-term care in Canada is a patchwork. Access to long-term care and its cost to individuals vary depending on the region where they live and whether they are still at home or in a residential facility. Whether they are on the road to a financially secure retirement or not, people are well-versed in the concept of saving for their golden years. But three quarters of Canadians have no financial plan to pay for long-term care if they needed it, according to a poll commissioned by the Canadian Life and Health Insurance Association (CLHIA).

The CLHIA estimates it will cost nearly $1.2 trillion to provide long-term care for the Baby Boomer generation as they pass through old age. Current government funding will only cover about half of this. That leaves a shortfall of $590 billion. What that means for the average Canadian is that now's the time to be saving specifically for the potential costs of their own extended care.

1 - 10.1 Costs over Time

Many chronic conditions requiring long term care can continue for years. The following chart looks at just a few examples of how these costs can add up over time.

Table 1-2 Long Term Care Chronic Illness Cost Analysis

Leading Cause	Typical Length of Care	Total Cost if in a Private Room	Total Cost if in a Semi-Private Room
Alzheimer's	96 months	$201,600	$163,200
Cancer	36 months	$75,600	$61,200
Cardiac	16 months	$33,600	$27,200
Diabetes	48 months	$100,800	$81,600
Pulmonary	36 months	$75,600	$61,200
Stroke	21 months	$44,100	$35,700

Source - Takincare Inc., 2010. Figures are based on an average Canadian monthly subsidized rate of $2100 for a Private room and $1700 for a semi-private room.

Canada is sleepwalking into a long-term care funding crisis and urgent policy action is required to ensure baby boomers will have access to the long-term care they need. Canadians are living longer, which is a good thing. But, as a result, they are increasingly likely to be managing a chronic disease through old age which, in many cases, will mean they will need some form of long-term care support. The challenges of a rapidly aging population for Canada's retirement savings and public healthcare systems are well understood. It makes good sense then that there is significant policy work being undertaken to address these issues.

Unfortunately, there is another very significant social policy challenge that is flying below the radar from a policy perspective: how to ensure that Canada can provide adequate long-term care support to baby boomers as they age.

1 - 10.2 Three Long Term Care Cost Scenarios

The following chart compares the cost of care under three separate scenarios: living at home; Caregiving; and alternate living arrangements. All figures reflect any Government subsidies.

As this chart demonstrates, the cost of care can range from manageable to sky-high.

Table 1 - 3 Caregiving Alternatives and Their Costs

Accommodation	Services	Monthly (low/high)	Annual
Living at home	Mortgage (if any),	$1,000 - $3,000	$12,000 - $36,000
	Utilities, cable, communication services,	$100 - $200	$1,200 - $2,400
	Shopping, cleaning, maintenance, upkeep, transportation.	$100 - $300	$1,200 - $3,600
	Renovations, Medic-alarm system, railings, elevators		$1,000 - $20,000 (One-time sum)
Caregiving	Private caregiving at home or in facility	$1,500 - $2,000	$18,000 - $24,000
	In-home nursing 5 days / wk.	$2,000 - $4,000	$24,000 - $48,000
	Respite care for family caregivers (weekends)	$500 - $700	$6,000 - $8,400
Alternative living arrangements	Ward room to private room in care facility Group residence Elder's residence Retirement home Residential nursing care	$1,700 - $2,100 $1,800 + $2,000 - $4,000 $1,909 - $6,000 $2,500 - $5,000	$20,400 - $25,200 $21,600 + $24,000 - $48,000 $22,908 - $72,000 $30,000 – $60,000

1 - 10.3 Provincial Variation

For elders who require care in a Long-Term Care facility, the costs tend to vary substantially from facility to facility and province to province.

Canada's provinces and territories differ substantially in the extent to which they subsidize long-term care, and, in the methods, they use to ensure good value for the money spent on it. Traditionally, government support has gone principally to individuals in licensed institutions such as nursing homes. In recent years, however, the supply of long-term care in the community has expanded for adults living at home and those in adult daycare and assisted daily living facilities.

In responding to this trend, each province has developed a unique array of subsidized programs that vary in ease of access and availability of services.

The provinces subsidize long-term care out of general revenues through a modified, non-universal safety-net model that is sometimes referred to as "targeted universalism." All offer needs-based programs that are universal in the sense that they are available to all residents who meet the needs-tests criteria. These programs, however, are targeted in the sense that recipients' co-payments are means tested. In defining recipients' ability to pay their share, all provinces and territories consider their declared income – indeed, Quebec and Newfoundland and Labrador also include assets.

In deciding on the subsidy for recipients of long-term care, provinces and territories distinguish between funding for what is referred to as "direct" services – case management, nursing care, physicians, and so on – and the associated charges for shelter, food, and housekeeping. In principle, individuals' co-payments are intended to cover all or part of the costs of living that recipients would be paying in any case if they still lived in the community. Patients staying in a licensed government-subsidized residential facility or using subsidized homecare services must pay these co-payment costs out of pocket or through private supplementary insurance – although, despite its availability, the latter is somewhat of a niche product in Canada, with only about 1 percent of Canadians age 65 and older currently owning private long-term care insurance.

For single individuals and couples, minimum facility-care fees are set according to Old Age Security (OAS) and Guaranteed Income Supplement (GIS) maximum monthly payments. Each individual living in a residential facility is also entitled to a minimum monthly allowance for personal expenses. Those with incomes greater than basic OAS/GIS levels face a claw back of their subsidy – that is, they must pay higher facility fees, up to a specified maximum. In most provinces, the claw back rate is 100 percent, meaning that patients must pay an additional dollar in fees for each dollar of income above the basic OAS/GIS threshold.

Alberta and Newfoundland and Labrador illustrate the variation in approaches to private long-term care charges. In Alberta, a single individual receiving care in a subsidized institution pays a maximum of roughly $20,676 annually out of his or her own pocket for (semi-private room) as a facility fee, reduced by about $1,000 if the individual's income is limited. In Newfoundland and Labrador, a single individual in institutional care pays a maximum of roughly $33,600 annually towards facility charges, reduced to around $13,500 annually if the individual's income is limited to federal OAS/GIS transfers and his or her assets do not exceed $10,000. Incomes above the federal old-age income maximum or assets above $10,000 normally are assessed at 100 percent, meaning that every additional dollar of earnings goes directly towards additional charges. Notably, the Yukon Territory, in contrast to the provinces, charges a flat, universal fee for facility-based long-term care – regardless of income.

Although most provinces assess income above OAS/GIS transfers at 100 percent until the maximum co-payment is reached, Saskatchewan claws back only 50 cents on every additional dollar above the OAS/GIS level until the maximum is reached, allowing residents of that province who need facility-based long-term care to keep a larger share of their income. It also reduces an unintended incentive that many middle-income seniors face under the current approach to income testing in most provinces: to deplete their income-yielding assets fully or pass them on to their heirs before going into a long-term care facility, to avoid dollar-for-dollar claw backs.

Table 1 - 4 Accommodation Rates (Subsidized) in Continuing Care Centres & Long Term-Care Residential Facilities (as of 2017/2018)

Province	Minimum Accommodation Rate	Maximum Accommodation Rate
Alberta	$1,636 / month – Standard Room (Ward)	$1,723 /month Semi-private room $1,992 / month Private room
British Columbia	$1,131 / month	$3,279 / month
Manitoba	$1,092/ month	$2,550/ month
New Brunswick	Depends on net family income	$3,437/ month
Newfoundland / Labrador	Depends on net family income	$2,800 / month
Northwest Territories	Poorer applicants can apply for an exemption	$808 / month
Nova Scotia	Depends on net family income	$3,300/month
Nunavut	Completely subsidized	Completely subsidized
Ontario	$1,819 / month Standard Room (Ward)	$2,229 / month Semi-private room $2,641 / month Private room
Prince Edward Island	Depends on net family income	$2,520 / month for Standard room

Québec	$1,142 / month Standard Room (Ward)	$1,535 / month Semi-private room $1,837 / month Private room
Saskatchewan	$1,101 Standard Room (Ward)	$2,727 Standard Room (Ward)
Yukon	$35 per day $1,050/month)	$35 per day ($1,050/month)

1 – 10.4 A Two-Tier System

The material above focuses on the costs associated with government subsidized long term care facilities. Increasingly – faced with long wait times – some Canadians will be forced to opt for private non-subsidized alternatives.

Residential long-term care is, for all meaningful purposes, excluded from Medicare. The *Canada Health Act*, the federal law that substantially defines Medicare, requires that provincial and territorial insurance plans pay for *medically necessary physician and hospital services,* be publicly administered, universal, comprehensive, accessible, and portable, with no extra billing or user charges allowed. While the *Act* refers to "extended health care services," which include LTC facilities, the federal government failed to promulgate regulations that would define those services, and it has never enforced these or other LTC standards as a condition of funding.

As in evidence above, in the absence of federal standards, there are enormous variations across provinces in the availability of services, level of public funding, eligibility criteria, and out-of-pocket costs borne by residents. Seniors with the same clinical profile and needs face disparities in access to beds and access to equipment, supplies and devices, depending on where they live and what financial resources they have. Inequality is widespread.

In short, residential long-term care in Canada is a two-tiered system. While all provinces regulate and subsidize LTC facility fees, eligibility criteria and means-testing methods vary widely. After paying monthly facility fees in publicly-subsidized facilities, many residents (a majority in some provinces) are left with a small "income allowance" ranging from $103 to $265 per month. From this, they must pay for medical and personal expenses that can include (depending on public subsidies): dentures, hearing aids, specialized wheelchairs and cushions, therapeutic mattresses, diagnostic tests, over-the-counter drugs, personal hygiene products, personal laundry, telephone, physiotherapy, foot care, and personal expenses like gifts and clothing. People who can afford to pay privately get a richer package of goods and services in publicly-subsidized facilities.

This is even truer of entirely private-pay LTC facilities, which are beyond the reach of most Canadians. In 2009, the average cost of a bed in British Columbia private-pay residential care facilities was $4,718 per month or $56,616 per year. As of 2005, in the same province, less than 5 per cent of unattached women over 65 and just over 11 per cent of unattached men over age 65 had incomes over $60,000 and therefore could afford a private-pay facility. Private-pay facility fees and income levels vary by province, but the picture is similar across the country: only a small minority can afford to live in wholly private-pay residential care facilities.

Private long-term care insurance is certainly not the answer – at least for most people. It is expensive, high-risk, and difficult to get. A 2006 review of Canadian LTC insurance products documented high and rising premiums, frequent rejection of applicants, caps on benefits and insufficient coverage, misleading advertising, difficulties with claims, and a confusing array of products, fees and rules.

As a way of paying for residential long-term care as a society, it is inefficient as well as unfair. Not surprisingly, only 1 per cent of Canadian seniors have private LTC insurance.

By 2056, the proportion of older seniors (age 80 and over) will almost triple to about one in 10, compared to about one in 25 in 2014. This cohort is most relevant to residential LTC, where the average age at admission was mid-eighties in 2014 (up from 75 in 1977). While demand for LTC beds is driven by many factors, an aging population is certainly a critical one.

The population is rapidly aging, and many seniors need residential long-term care, yet most provinces are reducing rather than expanding access to LTC beds. The number of LTC beds relative to seniors over 75 has been cut in all provinces except Ontario – by 7 per cent in Manitoba and Nova Scotia all the way up to 21 per cent in BC and Alberta. The expansion in Ontario has been almost entirely in the for-profit sector, where lower staffing is common and (with the elimination of legislated staffing levels in 1996) more money is diverted from direct care to company profits.

Cuts to LTC facility capacity have not been compensated by expansion in other parts of the health care system. In fact, hospital downsizing continued during this period in most provinces. Despite new investments in home and community care services in some provinces, non-residential long-term care services remain severely underfunded. Even with properly resourced services in other parts of the health care system, the demand for LTC beds will continue to outpace capacity if current trends continue.

Waits for LTC beds have become longer, and elders are forced to make difficult choices. Some must accept the first available bed, often at a facility they would not choose. This is especially the case for elders with specific cultural needs and those living in rural and remote communities. Couples are often separated, unable to get beds in the same facility or, in some cases, the same community. In some provinces, a person who refuses an offered space is moved to the bottom of the wait-list, forced to wait months, possibly years, for another opening.

1 - 11 LTC COSTS - WHOSE PROBLEM IS IT?

Responsibility for long term care is a hot potato. Depending on who you talk to, it is - variously - the responsibility of the individual, the family, the spouse, the employer, the community or, simply, the government. The debate is often heated … and it is about to get much hotter still. Health care costs have - for many years - been growing faster than Canada's gross domestic product. And the number of individuals requiring long term care will more than double in the next 30 years. Tens of billions of additional dollars will be required - on an annual basis - to meet the need. Where will these funds come from?

1 - 11.1 Individual Responsibility

Most books on personal finance, do not address the costs of long-term health care. And not surprisingly, most people do not bother planning for it.

When the need for long term care arises, it is generally too late to plan. Planning at this point involves desperately trying to hang on to whatever financial resources might exist. It is usually a losing battle.

Women are at particular risk. They live longer than men; are more likely to need long term care and have fewer financial resources; and are less likely to have a spouse present to help.

Even with more women in the workforce - financial inequality still exists.

1 - 11.2 Spousal Responsibility

Relying on the spouse to provide long term care only works well - for what should be obvious reasons - about half the time. The first spouse (usually the husband) benefits from the care, but who supports the survivor?

To make matters worse, the care provided to the first spouse often involves some financial burden. Such additional expenses as: hiring nurses, buying medications and equipment, remodelling a bathroom to accommodate a wheelchair are incurred.

This depletion of the couple's resources can end up severely compromising the survivor.

1 - 11.3 Community Responsibility

Most of us like to think that our spouse and children, perhaps even our friends, would quickly volunteer to assist us should we require long term care. Even if they are willing to care for us, it is not always possible.

Although children often plan to provide care or at least help to pay for it, they often have family and personal obligations that limit what they can offer.

Inevitably, one or two children end up doing most of the work. Those that are most likely to be willing to give their time are daughters.

This is not to say that sons are not willing to help—some do. Women simply tend to be most comfortable in the "care-giving" role. The physical aspects of caring for an ill or disabled person are not always pleasant. It involves bed changing, physical body washing, and other aspects that men are not always prepared to handle.

As the children become mentally and physically stressed to the limit, a Long-Term Care facility eventually becomes the only option.

Unfortunately, this often brings about an additional burden: guilt. Even though the children realize that facility care makes sense, they may feel they are letting their parents down.

1 - 11.4 Unrealistic Promises

Some parents place an additional burden upon their children. They ask them to promise never to institutionalize them under any circumstances. Of course, most children unwittingly agree and make a promise that is nearly impossible to keep. Even the parents probably have no idea themselves what they are requesting. If they knew, they may not have asked for such promises in the first place.

1 - 11.5 Corporate Responsibility

Most Employee Benefit plans do not cover residence in a Long-Term Care Centre. Nor do most of the union plans and retirement medical plans contribute to this coverage. The cost would simply be prohibitive for them to do so.

1 - 11.6 Government Responsibility

When all else fails, then it must be the responsibility of the government. It would certainly be comforting to think - that at the end of the day - the government will take care of us. It may even be in the short-term interests of politicians to suggest that this is the case.

The reality of the situation is far less comforting. Consider the following unpleasant facts:

- ❖ A government problem is "every taxpayer's problem.” In the end, it is the taxpayer who must put in the hours to earn the money to pay the taxes needed to pay for long term care. "Government sponsored" really means "taxpayer sponsored"
- ❖ Our government uses tax dollars to fund a wide range of social programs, not just medical care for the elderly. Those other programs will also be affected if there are not enough dollars to go around

- Our provincial health plans were never designed to address the long-term care needs of the elderly
- Governments are already cutting back on services and transferring health care costs to the individual - both to address increases in the number of elders and the sharply rising costs of medical care so will highly subsidized, quality government Long Term Care facilities be there when you need them? That is the million-dollar question.

1 - 12 LONG-TERM CARE INSURANCE

One method to plan is to purchase insurance designed to cover future health care costs.

Despite its' problems (as outlined above), one such form of insurance is Long Term Care (LTC) Insurance. LTC policies are relatively new in Canada, having only been on the market a short time in relation to other insurance products. They evolved because of a growing awareness of the need for people to pay for their own health care costs in their elder years.

Though new in Canada, such policies were introduced in the late 1970s in the United States and insurers in Canada have benefited from the experience of their U.S. counterparts.

As of 2018, there were only about 400,000 Canadians with long-term care coverage and the life and health insurance industry paid out benefits in excess of $12 million. The long-term care insurance market in Canada is underdeveloped. This differs materially from the situation in the U.S., where the long-term care market is much more developed, and consumers are more proactive in seeking coverage. There are over 10 million Americans that are protected by long-term care insurance.

The difference between the U.S. and Canadian markets is likely due to several factors. For instance, Canadians generally do not understand that there are limited government programs to support long-term care, many of which are income tested.

Therefore, in many cases governments will not cover the long-term care needs of Canadians. In addition, Canadians are generally sheltered from the costs of health care and, as a result, they are surprised at the price of long-term care solutions. Taken together, this impacts Canadians' demand for such coverage.

At some point, everyone must face the fact that they or a close friend or family member will end up needing long term care. Such care is expensive. Even those that remain primarily healthy will eventually develop physical or mental frailties, or impairments due to advancing age.

1 - 12.1 Responding to the Need

As we know, persons of any age can require long term care, not just the elderly. However, LTC policies are designed with the elderly in mind. Their role is to cover the costs of a variety of things, primarily home care and facility-based care. They do not include coverage for hospital or hospital related services. Nor do they cover the cost of doctor visits, or other types of care generally connected to the benefits provided under Provincial Health Plans. They pay a monthly benefit (usually calculated as a daily amount) for a specified time when the insured has satisfied certain conditions.

LTC policies provide peace of mind that may not be easily found elsewhere when it comes to long term care worries. Each policy will have benefits, exclusions, and limitations that are standard, so it is important to read the company's sales literature and policy contract carefully and deal through a reputable insurance broker that specializes in this area of insurance known as "Living Benefits."

Another form of insurance that deals with health care is Critical Illness Insurance (CI Insurance). Unlike Long Term Care insurance, which is directed at providing a regular monthly income to cover facility expenses and home care expenses, Critical Illness insurance is focused on specific major illnesses that are life threatening such as a heart attack or cancer.

This form of insurance pays a lump sum instead of a monthly income and payment is triggered when the individual suffers one of the specifically listed conditions.

1 - 12.2 Buying Long Term Care Insurance

Surprisingly, most companies do not offer Long Term Care insurance to people under the age of 40. This is beginning to change. Since prices are always lower at younger ages, buying early is attractive to people who want to develop a complete financial plan during their earning years that covers health costs after retirement.

Life Insurance companies have done much to offer exceptional policies, but the cost is not always affordable to those who need it most (older people with some physical ailments). Clearly, we must begin to consider such protection much earlier when age and health offer the best buys.

It has been estimated that 84% of those people who wait until they are age 70 or older cannot afford the premiums of adequate LTC protection.

1 - 12.3 Long-Term Care Policy Defined

A Long-Term Care policy is a contract that provides benefits for an extended period in some location other than a hospital. The exact benefits will vary, but each contract will have a policy schedule that states precisely what is covered.

It will include the elimination period, the maximum daily benefit for home and adult day care, the maximum facility care benefit and the maximum lifetime benefit.

LTC policies usually refer to two types of benefits, these being, Home Care Benefits and Facility Benefits. The amount payable may be the same regardless of whether care is being received at home or in a facility, or the policy may provide a different amount of benefit based on care location.

Payment of the benefit is triggered when the individual is unable to perform two or more Activities of Daily Living, or suffers a cognitive impairment of organic cause such as Alzheimer's disease.

1 - 12.4 Policy Structures

There are three different types of policy structures currently available in Canada for LTC policies. They are:

1. **Reimbursement Plans** which require the individual to submit receipts to the insurer who reimburses payment for those expenses deemed to be eligible expenses. This type of plan usually only offers a Home Care Benefit.

2. **Indemnity-Based Plans** which pay a specified daily or weekly amount without the need to submit receipts. The policy will define who can provide the care to the elder (e.g. a nurse through an independent agency versus a family member), and states where care can be received (e.g. At home, or in a facility as defined in the policy). This type of plan requires the individual to make all arrangements through a care coordinator at the insurance company. The care co-ordinator plays a "gatekeeper" role in ensuring the plan of care for the elder falls within the covered benefits of the plan.

This can be a useful feature because they also help the individual to access the community-based services.

3. **Income-Based Plans** which pay a specific fixed monthly benefit every month like an annuity payment. Under this type of plan, the insurance proceeds can be used however the individual wishes, care location is not defined in the policy and can be delivered anywhere by anyone, even a family member. This type of plan is the most flexible of all and has the highest premium as a result.

1 - 12.5 Definitions and Pricing

The more flexible a plan is, the more it will cost. Also, as a rule, plans that are more flexible once payment conditions have been met, have more stringent definitions that must be satisfied before payments will begin. For instance, all policies require the loss of ability to perform two or more ADLs. But what constitutes a "loss of an ADL" may be more strictly defined under one plan than under another.

For example, one plan might indicate an individual is "unable to dress themselves" if they cannot perform the task without verbal cueing, while another plan might not consider it a loss if the person can do so with verbal cueing.

Verbal cueing refers to giving the elder instructions such as “put your left leg in first.”

Some policies might limit what is an "institution." One policy might pay some benefits in an assisted living facility, while another may not.

1 - 12.6 Designing a Plan

The first decision that must be made when designing a plan is *how much benefit* to purchase. While everyone would love to purchase the maximum, which is in the range of $350/day, not everyone can afford to. Most people will purchase $100 to $150 per day.

An ***Elimination Period*** is selected – the number of days that must go by before benefits will begin. This is like a deductible in other forms of insurance.

The ***Maximum Benefit Period,*** also known as the *Overall Maximum Benefit Amount,* refers to the maximum benefit the plan will pay.

It may be indicated in years such as "5 years," or it may be stated as an overall dollar amount such as "$180,000."

There are often ***Optional Benefits*** that can be selected such as a "Return of Premium Benefit," which guarantees premiums are refunded if death occurs and no benefit has been paid out. Other options may include the right to buy more insurance regardless of changes in health (*Future Purchase Option*) and indexing of benefits to keep pace with inflation *(Cost of Living Adjustment*).

1 - 12.7 Two Valuable Features

There are many features included in the LTC policy as part of the basic contract. There is no additional premium charged for these provisions. Two noteworthy features are:

1. ***Non-forfeiture Provisions*** – The policy may provide that in the event premiums are not paid by their due date and the grace period has also passed, the policy will become a paid-up benefit for a reduced amount relative to how long it has been in force. This prevents someone from losing benefits altogether if they can no longer afford to maintain the plan after paying premiums for many years. Another form of a non-forfeiture clause is a Limited Term Period provision. Under this clause, when the insured can no longer afford to pay premiums, the policy stays in force for its original amount for a limited period, with the duration depending upon how long the policy had been in force.

2. A ***Waiver of Premium Provision*** is another valuable feature of LTC policies. Once the policy begins to pay a benefit, premiums are no longer required to keep the plan in force.

1 - 12.8 Long-Term Care Definitions

How Long-Term Care policies "define" certain terms is sometimes quite different from what our normal expectations might be.

Consider the descriptions of the following terms:

Home & Community Based Care

Care required and provided in a home convalescent unit under a plan of treatment; in an alternate care facility; or in adult day health care.

Home Convalescent Unit

- The insured's home, a private home
- A home for the retired, a home for the aged
- A place which provides residential care
- A section of a nursing facility providing only residential care
- It does not mean a hospital

Plan of Treatment

A plan of treatment is a program of care and treatment provided by a home health care agency. Each company may include additional information such as: (a) it must be initiated by, and approved in writing by, your physician before the start of home and community-based care; and (b) it must be confirmed in writing at least once every 60 days.

Home Health Care Agency

A home health care agency is an entity that provides home health care services and has an agreement as a provider of home health care services under a Provincial Government Medicare program.

Adult Day Health Care

This is a community-based group program that provides health, social and related support services in a facility that is licensed or certified by the Provincial Government as an Adult Day Health Care Centre for impaired adults. It does not mean 24-hour care.

Alternate Care Facility

A facility that is engaged primarily in providing ongoing care and related services to inpatients in one location and meets all of the following criteria: (a) provides 24 hour a day care and services sufficient to support needs resulting from the inability to perform Activities of Daily Living or cognitive impairment; (b) has a trained and ready to respond employee on duty at all times to provide that care; (c) provides 3 meals a day and accommodates special dietary needs; (d) is licensed or accredited by the appropriate agency, where required, to provide such care; (e) has formal arrangements for the services of a physician or nurse to furnish medical care in case of emergency; and (f) has appropriate methods and procedures for handling and administering drugs and biologicals. Many types of facilities would meet these criteria.

Medical Help System

A medical help system is a communication system, located in the insured's home, used to summon medical attention in case of a medical emergency.

Informal Caregiver

The informal caregiver is the person who has the primary responsibility of caring for the patient in their residence. A person who is paid for caring for the patient cannot be an informal caregiver.

Informal Care

Custodial care provided by an informal caregiver is considered informal care, making it unnecessary for the insured to be in a Long-Term Care facility or to receive such custodial care in the residence from a paid provider.

Caregiver Training

Training is provided by a home health care agency, Long Term Care facility, or a hospital and received by the informal caregiver to care for the insured in his or her home.

Respite Care

Respite Care includes companion care or live-in care, provided by or through a home health care agency, to temporarily relieve the informal caregiver in the home convalescent unit.

Maximum Lifetime Benefit

The maximum lifetime benefit is the total amount the insurance company will pay during the insured's lifetime for all benefits covered by the policy.

Medical Necessity

Care or services which are: (a) provided for acute or chronic conditions, (b) consistent with accepted medical standards for the insured's condition, (c) not designed primarily for the convenience of the insured or the insured's family, and (d) recommended by a physician who has no ownership in the Long Term Care facility or alternate care facility in which the insured is receiving care.

Long-Term Care Facility

A place which: (a) is licensed by the province where it is located; (b) provides skilled, intermediate, or custodial nursing care on an inpatient basis under the supervision of a physician; (c) has 24-hour-a-day nursing services provided by or under the supervision of a registered nurse (RN), licensed vocational nurse (LVN), or a licensed practical nurse (LPN); (d) keeps a daily medical record of each patient; and (e) may be either a freestanding facility or a distinct part of a facility such as a ward, wing, unit, or swing-bed of a hospital or other institution.

A Long-Term Care facility is not a hospital, clinic, boarding home, and a place, which operates primarily for the treatment of alcoholics or drug addicts, or a hospice.

Even so, care may be provided in these facilities subject to the conditions of the Alternate Plan of Care Benefit provision, if one exists in the policy.

Inability to Perform Activities of Daily Living

This is described as the insured's dependence on someone else because of the need, due to injury, sickness, or the frailty of age, for regular human assistance or supervision in performing Activities of Daily Living.

Activities of Daily Living

These will vary from company to company and from policy to policy. Most companies require that the claimant be unable to perform a minimum of two ADL’s in order to receive the benefit.

The activities listed are very important because they determine the conditions under which payment will be made. Policies that list eleven conditions may be more favourable for the policyholder than those that list only five. However, this depends on how *strict* the actual wordings of the conditions are.

The older one gets, the more likely the need for some sort of care. This is not necessarily due to illness or injury; it can be due to simple old age.

Typically, however, the need is a combination of illness and old age. Most facility care policies underwrite using, in some form (and must state the inability to perform two or more of the listed ADL’s to qualify), a set of activities of daily living.

While the activities used can vary, they commonly include some variation of the following. Activities of Daily Living (could be a combination of any of the following):

- Eating
- Bathing
- Dressing
- Toileting , Continence
- Transferring

In addition, the elder may be asked by the insurance company about their abilities in the following areas, commonly referred to as Instrumental Activities of Daily Living (IADLs):

- Traveling outside of the home
- Keeping track of household finances
- Meal preparation
- Housework or outside chores
- Telephone use or taking oral medications appropriately

The general opinion is that active people will not be as likely to need nursing home care. Physically, they will be in better condition. A person's ability to perform these daily activities gives the insurance company an indication of their general health and mental well-being.

Cognitive Impairment

Cognitive impairment is the deterioration in the insured's intellectual capacity, which requires regular supervision to protect themselves and others.

This often must be determined by clinical diagnosis or tests.

Cognitive impairment may be the result of Alzheimer's disease, senile dementia, or other nervous or mental disorders of organic origin.

Pre-existing Condition

A pre-existing condition is a health condition for which the insured received treatment or advice within the previous 6 months of application for coverage.

Effective Date of Coverage

The date listed on the Policy Schedule page, which states the first date of coverage under the policy is the effective date of coverage. It is not necessarily the date of policy application.

Elimination Period

The elimination period is the number of days that covered Long Term Care facility or home and community-based services are provided to the insured before the policy begins to pay benefits. This period will be shown on the Policy Schedule page.

1 - 12.9 Evaluating the Policy

There are six considerations to look at when trying to decide what type of LTC policy is right for the elder.

1. **No policy is perfect.** You will probably like certain features in one plan and other features in another plan. Pick the one that is most right for you and fits comfortably within your premium-paying ability. No one plan is perfect and each person's needs and likes differ.

2. **Flexibility in types of care.** Does the LTC policy limit where care can be received and who can provide the care. If so, even if your aunt or son is a qualified registered nurse, the policy may not pay benefits. Also, certain institutions may not qualify as a "facility" for the facility benefits. Look for limitations on where care can be provided.

3. **Ease of qualifying for benefits**. Check how strict the definitions that describe what constitutes a loss of an Activity of Daily Living are.

4. **Safeguards against forgetting to pay a premium**. Does the policy include a Non-forfeiture Provision? What about a Grace Period extension? Can you register an alternative contact name with the insurer that will be notified if the elder forgets to pay a premium?

5. **Guarantees against future premium increases.** Since LTC policies are still relatively new in Canada, the industry can be expected to go through some further price refinement as they develop more experience with claims rates. Policies are guaranteed to be renewed if you pay the premium, but the contract does not guarantee that the rate will never change.

   In fact, the insurer has the right under most contracts to increase premiums for a group of insured's (not an individual alone) if they need to do so. Some policies will provide a written guarantee how often or how high the maximum increase will be.

6. **The cost today.** Just as everyone does not drive a Mercedes, similarly not everyone needs or can afford the most expensive LTC policy. Purchase what you can afford to maintain. Remember that having some benefits is better than none. Some insurers offer discounts to couples who purchase their policies at the same time when they purchase identical contracts.

1 - 12.10 A Long-Term Care Checklist

1. What services are covered for Nursing home care, Home care, Home health care, Assisted living facilities, Adult day care, Alternate care, Respite care, others?

2. How much does the policy pay per day for nursing home care? For home health care? For an assisted living facility? For adult day care? For alternate care? For respite care? For other services?

3. How long will benefits last in a nursing home? At home? In an assisted living facility? Elsewhere?

4. Does the policy have a maximum lifetime benefit? If so, what is it for nursing home care? For home health care? For an assisted living facility? For other facilities?

5. Does the policy have a maximum length of coverage for each period of confinement? If so, what is it for nursing home care? For home health care? For an assisted living facility?

6. How long must I wait before pre-existing conditions are covered?

7. How many days must I wait before benefits begin for nursing home care? For home health care? For an assisted living facility? For other facilities?

8. Are Alzheimer's disease and other organic mental and nervous disorders covered?

9. Does the policy require the following: an assessment of activities of daily living? An assessment of cognitive impairment? Physician certification of need? A prior hospital stay for nursing home care? Home health care? Prior nursing homes stay for home health care coverage? Other?

10. Is the policy guaranteed renewable?

11. Is there a waiver of premium provision for nursing home care? For home health care?

12. How long must I be confined before premiums are waived?

13. Does the policy have a non-forfeiture benefit?

14. Does the policy offer an inflation adjustment feature? If so, what is the rate of increase? How often is it applied? For how long? What is the additional cost?

15. What does the policy cost? Per year? Per month?

Table 1 – 5 Is Long-Term Care Insurance Protection Worth the Premium?

Long Term Care Breakeven Analysis Hypothetical Example: Husband and Wife, Each 65 / Daily Benefit Amount: $100 per day Elimination Period: 100 days / Benefit Period: 3 years / Monthly Premium: $200	
Years and Total Premium Paid	**Amount of Time for Benefits to Equal Premiums Paid**
2 ($4,800)	Less than 2 months
5 ($12,000)	4 months
10 ($24,000)	8 months
20 ($48,000)	16 months
A small period of Long-Term Care benefits may quickly offset the costs!	

1 - 13 LONG-TERM CARE - ALTERNATIVE FUNDING

Not everyone agrees that the purchase of an insurance policy is the appropriate avenue. For some people, it is not prudent to purchase a Long-Term Care insurance policy if their financial situation does not permit. However, for those who can afford the premiums, it may be worthwhile.

1 - 13.1 Investing to Fund Long Term Care

Any method of investment or long-term care funding that produces a pool of money could be considered as an alternative to an insurance policy. It would not matter whether the funding came from stock profits, or an inheritance. Funding is funding. If it produces enough money to pay for long term care services, then it is an alternative to an insurance policy.

Now let us be realistic. Investing successfully is one thing and having the funds set aside purely for long term care is another. The problem is one of timing.

Generally, the need for long term care comes as life is ending. The chance of putting money aside and using it for nothing else is small. It can be done; it just is not likely to be done.

1 - 13.2 Major Medical Coverage

With few exceptions, private major medical insurance does not cover long term nursing home care. Only policies specifically designed to cover such expenses will do so.

The general type of medical policies carried for major medical coverage exclude long term care benefits in a facility. Receiving long term care in an institution is expensive. The better the institution, the more expensive the care will be. It is also more expensive in some areas of the country than others. The time to find out what these costs will be is not when the care is needed. Costs should be explored in advance of medical need. Also, consideration should be given to where you plan to retire.

If your career has taken you to Ontario, but you plan to retire "back home" in Nova Scotia, you may be in for a surprise at the difference of long-term care costs in another province.

Few people could afford to (or would want to) pay for nursing home costs out of pocket. While some may be able to do so, it is not necessarily the wisest course of action. Some individuals do elect to fund only a portion of nursing home costs, expecting to pay the balance from current living budgets.

1 - 13.3 Self-Pay

Many households end up paying, at least initially, for the long-term confinement of a member in a Long-Term Care centre. Sometimes this "self-pay" is not intentional; they simply did not plan for this circumstance. In other cases, it was intentional.

The household members felt they had the ability to do so if the need arose, or they simply did not believe that such a condition would ever exist for them personally. It would always happen to that mysterious "other person."

For those who did plan to self-pay, there was hopefully some thought put into it beforehand. Perhaps the individuals looked to their family heritage and did not see a history of health conditions that would make a facility confinement likely.

In addition to a review of their family's health history, they also should have looked at the financial aspects of a long facility confinement. The financial devastation brought on by a nursing home confinement can be minimized to some degree. In some situations, it may even be avoided.

1 - 13.4 Paying Family Members

For some individuals, paid family members are a solution if a long-term illness or injury arises. Usually their care needs are the result of physical, mental, or emotional problems, which makes living alone dangerous.

The family members must be willing to take on the job of caring around-the-clock for the elderly family member. Some families willingly accept this chore and can devote the necessary time to it. In some cases, help from outside agencies may be able to supplement the care the family gives.

Whether or not this outside help was covered by insurance policies or government aide will depend upon multiple factors. Payment to a family member for services is generally not a deduction for Income Tax purposes, while any payment to an official agency usually is. For the sake of planning, the family or individual should not depend upon payment from other sources.

Any individual who plans to rely upon their family for their care must understand that they are taking a chance. No matter how willing the family may be today, it will be difficult to assess their availability in the years to come. Family situations change; emotions change; financial circumstances change (the potential caretaker may have to take a job, for example); and the family's willingness to take on the chore may change. In addition, taking in a family member affects everyone in the household, not just the actual caregiver.

There must be ample room in the house and financial resources must be available. Everyone in the family is likely to give up something when an elderly person moves in.

Attempting to use financial means to ensure care by a family member can also backfire. Perhaps they tied their care into a will or trust; perhaps an agreement was drawn up. Whatever the case, there is still no guarantee that it will work. In addition, if the potential caregiver is providing care against their will, what kind of care will they be delivering?

In fact, even well-intentioned family members have been known to deliver poor care. Long Term Care centres reported that a substantial number of patients coming from private homes have bedsores and other physical problems.

1 - 13.5 Government Funding

Unfortunately, Government funding is unlikely to be a major factor in funding a person's health care costs in their elder years. Government programs in the past have contributed or paid for health care for those people who could not afford to do so. As previously mentioned, downloading is occurring and the bulk of the financial commitment is being passed down to the individual.

As we know, the Government does not handle the costs of long-term care. The various government health plans do a good job with hospital and doctor bills, but the limited amount of skilled care offered by the different levels of government is not adequate and cannot be considered coverage on a long-term basis. The best way to know what costs you ultimately face in your elder years and to plan for them today is to work with a specialist in the area of living benefits and they can help you to do a proper Needs Analysis.

1 - 14 CONCLUSION

Long-term care is certain to become a rapidly growing component of provincial healthcare expenditures in the years to come. As Canada's society ages, more personal care and health support will be needed for people who, either because of disability or aging requires assistance to function independently. As this happens, policymakers, in the face of existing fiscal burdens and the increased demands that lie ahead, must balance caring for individuals with long-term needs and the burden on future taxpayers. This is a thorny challenge. But policymakers should tackle these tough issues now, before the first wave of baby boomers begins to draw heavily on long-term care programs in about 15 years' time.

Policy reforms will require methods to contain costs, to fairly divide these costs between care recipients and taxpayers, and to get more value for money in a sector that will feature prominently in future economic policy debate. There is no obligation under the *Canada Health Act* for the provinces to provide universal long-term care without private charges; instead, provincial governments will decide on such issues as the level of public support versus private charges, eligibility criteria, and standards of quality for long-term-care delivery. Diversity in provincial approaches is healthy, and more comparative analysis of the experience in different provinces, as well as in other countries, would be helpful in developing future policy.

While the provinces clearly must subsidize long-term care for those who lack the means to pay for it, for other Canadians with substantial resources (both income and assets) a more targeted approach is needed. In designing the targeting rules, provinces should find ways to treat assets flexibly for elderly couples when one spouse has high long-term-care needs and the other spouse remains in the community. Further, so as not to unduly discriminate against middle-income seniors with accumulated savings, the provinces could establish a more gradual scale to reduce the size of public subsidies, one that does not reduce the subsidies by one dollar for each additional dollar of private income or assets.

Private insurance to help pay for long-term-care costs could be encouraged, especially for seniors who wish to pass on assets to their heirs and might reduce the need for public subsidies to a limited extent.

Perhaps most important, governments must aim to get good value for the money they spend on long-term care, and on this score, there are many opportunities to improve efficiency in the sector – some European countries seem to be far ahead of Canadian provinces in doing so. Reforms should insist on measures that eliminate the waiting lists that currently exist for many services and improve the location of care around patients' preferences.

The goal is to work towards a health system that provides quality care and addresses the unique needs of patients, families, caregivers, and health professionals throughout the country.

Unfortunately, a lot more than good intentions will be needed to address the pressures that will soon be placed on Canada's health care system.

For most Canadians, the best approach is likely to hope for the best, but plan for the worst. And that involves taking individual responsibility for one's own long-term care needs.

1 - 15 REFERENCES

Canadian Institute for Health Information, Dec. 18, 2003

Congress of Union Retirees of Canada (CURC), 2006 – Ottawa, ON

Evaluating Long Term Care Insurance by Jacqueline Figas, CLU, EPC, published by CCH Canadian Limited. 2000

Health Canada – www.health.gov.on.ca

Home care statistics - McDonald McCleary and Daciuk, 1998

Instrumental Activities of Daily Living Scale, MP Lawson, EM Brody (1969). The Gerontological Society of America.

Living with dignity, Ms. Micheline Varas, BA, RHU, RFC, EPC Vice-President Living Benefits - Equinox Financial Group Customplan - Vancouver, BC

Long Term Care for the Elderly: Challenges and Policy Options, C.D. Howe Institute, November 2012

National Population Health Survey, Statistics Canada, 2002/03 & the Romanow Report

Not Your Grandmother's Retirement Home, Globe & Mail, July 22, 2013

Report on Long-Term Care Policy, CLHIA, 2012

Residential Long-Term Care in Canada, CUPE, October 2009

When a Nursing Home is Home, Canadian Institute for Health Information, 2013

Chapter 2

Housing Options

---

2 - 1 KEY OBJECTIVE OF THIS CHAPTER

The following material looks at the broad spectrum of different housing options available to Canadian elders. This chapter will also offer you some perspective on the issues and concerns that drive elder housing decisions.

Having some understanding of these matters should help you to assist elders and their families in ensuring their housing choices are safe and suitable - and that they offer them the highest possible quality of life.

2 - 1.1 How Will This Objective Be Achieved?

We will look in detail at some of the things that can be done to ensure that elders are able to stay in their own homes if possible. Home care, home modifications, and adult day care centres can all be of significant assistance in this regard. This chapter will also cover such matters as:

- Elder housing challenges
- Safety issues and steps that can be taken to reduce risk
- Geriatric Case Management - and its role in assessing elders and making housing recommendations
- Things to consider in selecting an institution
- The various institutional options available
- Government assistance programs

2 - 2 INTRODUCTION

Most elders have a strong desire to remain in their own homes if possible. Given the cost of institutional care, society also has a strong incentive to assist them in this regard.

More than 90% of Canadians age 65 and older continue to live in their own homes. This is a testament both to their own health and to the wide array of assistive products and services that are available.

2 – 2.1 Aging in Place

Aging in place is something that is desired by most Canadian elders. Unfortunately, the term “aging in place” can have several meanings.

For some elders, it means staying in the same house they have occupied for years or decades, such as the house in which they raised a family. But it may mean simply staying in the same community, although in a different (usually smaller) building. In some contexts, aging in place means any alternative to moving to a long-term care facility, such as renting an apartment that offers extra supports for living.

About 85% of Canadians over 55 years old want to remain in their present home for as long as possible, even if there are changes in their health. Meeting this demand will require adaptations to existing housing, home maintenance and support services. It will also likely require personal care from family, friends, and neighbours, and increased reliance on both government and private service providers.

Future technology may also prove to be of assistance. An abundance of research is currently under way on smart technologies for aging — a field known as “gerontechnology” — to develop everything from wireless home monitoring systems to assistive robotics to support those who want to stay in their homes. This is a rapidly evolving field, and housing providers will benefit from staying abreast of developments in this area, given that aging baby boomers are more comfortable with technology than previous generations of seniors, and have higher expectations for smart technology that offers convenience, safety, and connectedness.

As desirable as aging in place may be, it is important to note that aging in place may be inappropriate for seniors living in older structures that require extensive ongoing maintenance. Newer forms of housing that do not require frequent repairs and that can easily be fitted with supports as their residents age may be a more comfortable choice.

The best way of looking at aging in place is to consider that *all* housing providers are, in a sense, providing housing for seniors, if not immediately, then in the long term. Ideally, any housing unit anywhere should be adaptable as its resident’s age.

Design features that facilitate aging in place can be incorporated into the original design plans of a project. These features are generally unobtrusive and roughing them into the original construction costs a fraction of what it would cost to add them later. They can also be a selling feature: even if some current buyers do not plan to live in the unit long term, they will be interested in any feature that could add to the resale value.

Finally, it is important to remember that eventually there may come a time when staying at home is no longer a viable option. Some form of institutional care may become a necessity. When and if the need arises to move an elder into an institution a great deal of care must be exercised.

2 – 3 ELDER HOUSING OPTIONS

There is a broad array of housing options available to elders, from staying in their own home to specialized facilities that provide round-the-clock nursing care. The names of the different types of housing options can sometimes be confusing, as the terminology can vary from region to region. However, in general, the different types of senior housing vary according to the amount of care provided for activities of daily living and for medical care. When researching elder housing options, elders should make sure that whatever they are looking at covers their required level of care and that they understand exactly the services offered and the costs involved.

2 – 3.1 Option One: Staying at Home

Staying at home has the advantage of keeping an elder in a familiar place where he or she knows the neighbours and the community. As noted above, to assist elders who decide to stay in their own homes, there is a wide range of home services available. It is also possible to initiate home repairs or modifications to make life at home easier and safer, such as installing a wheelchair ramp, bathtub railings, or emergency response system.

Staying at home may be a good option if:

- The elder has a close network of nearby family, friends, and neighbours
- Transportation is easily accessible, including alternate transportation to driving
- The neighbourhood is safe
- The home can be modified to reflect changing needs
- Home and yard maintenance is not overwhelming
- The elder’s physical and medical needs do not require a high level of care
- The elder has a gregarious personality and is willing and able to reach out for social support

Staying at home is a less effective elder housing option if the elder's mobility is limited. Being unable to leave home frequently and socialize with others can lead to isolation, loneliness, and depression. So, even if an elder decides to stay in his own home today, it is important to have a plan when needs may change and staying at home may no longer be the best option.

2 - 3.2 Option Two: Independent and Active Lifestyle Accommodation

This type of accommodation is often referred to as an adult lifestyle community. It allows elders to maintain their own homes without any need to rely on family and friends. Members of the community can access specialized programs and services, such as transportation to the grocery store, home health care, or help with household chores, as well as a network of social activities with other community members.

These communities may be apartment complexes, condominiums, or even free-standing homes. In general, the housing is friendlier to older adults—it is more compact, easier to navigate, and includes help with outside maintenance. Sometimes recreational centers or clubhouses are also available on site.

An elder may want to consider independent living if:

- He starts needing minor assistance with activities of daily living
- He would like a place that does not require a lot of maintenance and upkeep
- He likes the idea of socializing with peers and having activity options nearby

2 – 3.3 Option Three: Assisted Living Accommodation

In general, assisted living is a housing option for those who need help with some activities of daily living, including minor help with medications. Costs tend to vary according to the level of daily help required, although staffs is available 24 hours a day.

Some assisted living facilities provide apartment-style living with scaled-down kitchens, while others provide rooms. Most facilities have a group dining area and common areas for social and recreational activities.

An assisted living facility may be a good choice if:

- The elder needs more personal care services than are feasible at home or in an independent living retirement community
- The elder does not need the round-the-clock medical care and supervision of a nursing home

2 – 3.4 Option Four: Long Term Care

A Long Term Care facility or nursing home is normally the highest level of care for older adults outside of a hospital. While they do help in activities of daily living, they differ from other senior housing in that they also provide a high level of medical care. A licensed physician supervises each resident's care, and a nurse or other medical professional is almost always on the premises. Skilled nursing care and medical professionals such as occupational or physical therapists are also available.

A nursing home may be a good choice if:

- Both the elder's medical and personal care needs have become too great to handle at home or in another facility. This may be due to a recent hospitalization, or a chronic illness which has gradually been worsening.
- The elder needs a higher level of care temporarily after a hospitalization, but it is anticipated that he will be able to return to home or to another facility after a period.

2 – 3.5 Assessing the Need

When evaluating an elder's housing needs, the following issues should be taken into consideration:

- **Level of Care** - No one can predict the future. However, if the elder has a chronic medical condition that is expected to worsen over time, it is especially important to think about the common complications associated with the condition, and how they will be handled.
- **Location and accessibility -** Even if the elder is completely independent currently, circumstances can change. It pays to think a little about future circumstances. For example, how far is the elder's home from shopping, medical facilities, or other services? If the elder can no longer drive, what kind of transportation access is available? Can the elder's home be easily modified? Does the home have a lot of steps or a steep hill to navigate? Does the home have a large yard that needs to be maintained?
- **Social support -** How easy is it for the elder to visit friends, neighbours, or engage in hobbies? If it becomes difficult or impossible for the elder to leave the home, isolation and depression can rapidly set in.
- **Caregiving Support -** Even if family members can commit to caregiving, they might not be able to fill in all the gaps if physical and medical needs become extreme.

- **Finances -** Making a budget with anticipated expenses can help the elder weigh the pros and cons of his situation.

  Senior housing options like assisted living can be expensive, but extensive in-home help can also rapidly mount in cost, especially at higher levels of care and live-in or 24-hour coverage. The elder may be able to purchase insurance to offset some of the costs of long-term care. And some limited government support may be available.

- **Professional assessment.** Geriatric care managers can provide an assessment as well as assistance with managing the elder's situation, including crisis management, interviewing in-home help, or assisting with placement in an assisted living facility or nursing home.

2 – 3.6 Segmenting the Market

The housing needs of their elder market are far from homogeneous. To better understand the needs of various groups of elders, it makes sense to segment the market by age, lifestyle, income, cultural affiliation and needs. All these factors will have an impact on what constitutes suitable housing.

Age

Older Canadians are often grouped into the following four age cohorts: pre-seniors, aged 55 to 64; younger seniors, aged 65 to 74; older seniors, aged 75 to 84; and elderly seniors, aged 85 and older.

Historically, the two most significant transition points along this aging spectrum were (1) the time of retirement and (2) the age at which health starts to play a bigger role in defining accommodation requirements. However, these transition points are becoming blurred and generally occur later in people's lives than has been assumed in the past. Today, the mean age at which residents move into seniors housing development is estimated to be close to 85, and the average age of residents is older still.

A supportive housing project or long-term care facility targeted to, say, the entire over-65 group may therefore find that it has grossly overestimated the pool of prospective residents. As noted earlier, most Canadian elders are not in institutions and they are leading active and independent lives.

Lifestyle

Grouping people exclusively by age frequently misses subtle differences among older individuals. Segmentation by lifestyle offers a finer degree of distinction. Lifestyle segmentation categorizes individuals according to how they prefer to spend their time, what they consider important about their immediate surroundings, their opinions on various issues, and their interests, regardless of age.

For most elders – particularly those under the age of 85 – housing decisions are made largely based on "wants" rather than "needs."

One approach to lifestyle segmentation looks at elders in terms of their degree of independence, desired amenities and health care needs. Another popular approach groups seniors into six categories (explorers, adapters, pragmatists, preservers, martyrs and attainers) based on defined character traits, and then combines these traits, with other factors such as health status, income, introversion/extroversion, family status and age in order to determine the best housing "fit."

Income and Assets

Another driver of elder housing decision is income and assets. Assets (of which peoples' homes are generally the largest) can help determine the level of financial resources available to older Canadians when considering various housing options. It is common to estimate the income that would be generated if the home owned and occupied by seniors in the primary market area were sold, the proceeds converted to cash and the money invested. This calculation requires estimating not only the average value of homes in the catchment area but also residual mortgage values and the rate of mortgage free homeownership among those within the target age cohort.

When a housing option involves an upfront investment such as a condominium or a life-lease suite, the rate of homeownership, the value of the homes and the amount of remaining mortgage on the homes can indicate whether the target group has the assets to afford the purchase price or ongoing occupancy or co-payments.

Cultural Affiliation

Cultural segmentation is becoming more and more common as the ethnic diversity of the Canadian population increases. Just as culturally based values influence the purchase of other goods and services, they can drive housing preferences and the demand for various forms of accommodation. The two most common cultural factors affecting housing choice are ethnicity and religious affiliation.

At the same time, within different ethnic communities, characteristics such as education, occupation, income and lifestyle may vary widely. As a result, when segmenting by ethnicity, it is important to use other segmentation approaches as well. Even within a ethnic community, housing preferences and needs may differ according to factors such as time of immigration.

Segmentation by religious affiliation is like segmentation by ethnicity. Just as there are a range of demographic profiles among different ethnic communities, so too are there a range of profiles among faith groups. Other factors such as age, income and lifestyle should, therefore, also be considered.

Distinct Needs

Segmentation by need can be one of the most reliable ways of subdividing the seniors' housing market, particularly when there is a need for personal or health care services. Seniors' needs can, however, affect other factors beyond the provision of services. In some cases, social needs are a major consideration. This can include how desirable elements such as outside seating areas, libraries, game rooms and larger common areas more suited for social interaction might be.

Sponsors of rural developments may have to provide a more extensive range of "in-house" programs and services, as there will typically be few other providers in the immediate community who can offer such services. Sponsors of projects in urban areas may provide more limited services if there are other options available in the area.

2 - 4 ELDER LIVING ARRANGEMENTS

According to Statistics Canada's projections, there were over 6 million seniors aged 65 and over in Canada in 2017. Of these individuals, 92.1% lived in private households or dwellings (as part of couples, alone or with others) while 7.9% lived in collective dwellings, such as residences for senior citizens or health care and related facilities. These proportions were relatively unchanged from 2001 when 92.6% of the senior population lived in private households and 7.4% lived in collective dwellings.

At the oldest ages, fewer people lived in private households, specifically in couples, and comparatively more lived in collective dwellings, especially women.

2 - 4.1 Living as a Couple

Among the population aged 65 and over – according to the most recent census data - the majority (56.4%) lived as part of a couple; a higher proportion than what was the case back in 2001 (when only 54.1% lived as a couple. More than 7 in 10 senior men (72.1%) and over 4 in 10 senior women (43.8%) lived in a couple.

The prevalence of living in a couple declined with age. Among seniors aged 65 to 69, 70.0% lived as part of a couple, although this was higher for men (77.9%) than for women (62.7%). For the oldest age group, aged 85 and over, fewer seniors were in couples. Still, more than one-fifth (21.9%) of this age group lived with a married spouse or common-law partner: 46.2% of men and 10.4% of women.

An elder's living arrangements have a significant impact on whether there is a need for outside assistance. Not surprisingly, elders who are living alone tend to have more need for assistance (e.g., home care, nursing care, etc.) than elders who do not live alone.

2 - 4.2 Women Living Alone

The most recent census data showed that about one-quarter (24.6%) of the population aged 65 and over lived alone, down from 2001 (26.7%). The share of the population that lived alone was low and stable until about the age of 50 for women, and until approximately age 70 for men. Over these ages, the prevalence of living alone increased for both sexes, but more sharply for women.

At younger ages, living alone was more common for men than for women. However, among seniors aged 65 and over, women were nearly twice as likely to do so—31.5% compared to 16.0% of men. This relates in part to the lower life expectancy of males, compared to females, and to the tendency for women to form unions with spouses or partners who are slightly older than themselves. As a result, senior women were more likely than senior men to be widowed, many of whom subsequently lived alone.

Between 2001 and now, the proportion of senior women who lived alone declined while the proportion of senior men living alone remained relatively stable. The largest decrease in the share of women who lived alone occurred among those aged 80 to 84 - 40.2% of women in this age group lived alone, down from 46.1% in 2001. The number of men in this age group, who lived alone, fell from 20.1% in 2001 to 18.6%.

The larger decline among senior women may have been partly since life expectancy for men has increased at a faster rate than for women in recent years. Consequently, proportionally more senior women remained in couples until older ages.

Among the age group 85 and over, 36.6% of women lived alone compared to 21.8% of men.

2 - 4.3 Living in Senior Residences

The most recent census data counted 127,925 seniors, 2.6% of the population aged 65 and over, living in residences for senior citizens. About 72.3% of them were women and 27.7% men.

Most persons aged 65 and over (83.9%) in residences for senior citizens were living alone. In the age group 65 to 74, the proportions of men and women living alone in a residence for senior citizens were similar (82.5% for women and 81.3% for men).

Among the age group 85 and over, 86.9% of seniors in residences for senior citizens were living alone. The share of women in this age group living alone (92.2%) was higher than for men (70.6%). In contrast, the share of seniors living in residences for senior citizens as a couple was higher for men - 17.2% of men aged 65 to 74 lived in a couple, compared with 15.7% for women. In the oldest age group, 85 and over, this proportion was 28.8% for men and 6.7% for women.

2 - 4.4 Proportion of Seniors in Special Care Facilities

As people age, they are more likely to live in collective dwellings that provide ongoing support and assistance services, professional health monitoring, care and treatment.

352,205 seniors aged 65 and over, or 7.1% of all seniors, currently live in a collective dwelling that focuses on special care to seniors. The prevalence of seniors living in special care facilities, such as nursing homes, chronic care and long-term care hospitals and residences for senior citizens, increases with age. Among the age group 65 to 69, about 1% live in special care facilities; among seniors aged 85 and over, the proportion was 29.6%.

The proportion of seniors living in special care facilities was similar among women and men aged 65 to 74. However, past the age of 75, the prevalence of living in this type of collective dwellings increased considerably for both sexes, but at a different pace. Among women aged 85 and over, the share in special care facilities was 33.4%, compared to 21.5% for men.

2 - 4.5 Adding Up the Senior Population

The following table shows the breakdown of Canada's over age 65 population and what type of dwelling they were living in according to Statistics Canada's Census of Population.

Table 2-1 Dwelling Arrangements for the 65+

Total Population 65 + - 4,945,000		
Type of Facility	**Population**	**% of Seniors**
Private Dwellings	4,551,905	92.1
Collective Dwellings	393,095 (224,280 in nursing homes, 127,925 in seniors retirement residences, 40,890 in other collectives)	7.9
	TOTAL	100%

Source: Statistics Canada, 2018 (data from the 2011 Census).

More than half (57%) of the Collective Dwellings indicated above are Nursing Homes, Chronic Care facilities or LTC Hospitals. A third of these dwellings are Retirement Homes.

2 - 4.6 Living in a Single Detached House

Census data show that the share of the population living in a single-detached house varies as individuals age. Among younger age groups, the proportion of men and women who lived in a single-detached house was similar. The prevalence of living in this type of housing declined for both sexes once individuals reached the age of 55. The decrease was more pronounced for women.

The differences between women and men were more apparent in the oldest age group - 66.5% of men aged 65 to 69 lived in a single-detached house, compared with 60.4% of women. However, among seniors aged 85 and over, 44.3% of men lived in a single-detached house, compared with 30.9% for women.

The share of seniors living in collective dwellings increases with age - 393,095 seniors aged 65 and over, or 7.9% of all seniors, living in a collective dwelling. Among seniors aged 65 to 69, 1.6% lived in a collective dwelling as compared to 31.1% for seniors aged 85 and over.

2 - 4.7 Home Ownership

A substantial majority of elders own their own home. According to the 2016 Census, roughly three quarters (74.6%) of all households headed by an elder (age 65 and over) owned their own home. In the case of elders between the ages of 55 and 64, 76.3% owned their own home. Home ownership rates drop somewhat at younger ages. Only 43.6% of households headed by someone between the ages of 20 and 34 own their own home.

Elders who are living in families are far more likely to own their own home than elders who are living alone. Only 43% of unattached elders own their home - compared to over 80% of elders who headed up multi-person households.

Also, of significance is the fact that 58% of the homes that are owned by Canadians, who are 65 years of age and older, are mortgage free.

2 - 4.8 Elders Who Rent

One half of elders living alone rented their dwellings, compared to one fifth of families headed by an elder. Generally, for elder households who rent, the proportion of total income devoted to rent is higher than it is for other Canadians.

Having said this, there is strong evidence to suggest that the choice to rent (versus own) among elders is often based on convenience and flexibility rather than necessity.

2 - 4.9 Social Housing

As with other lower income segments of the population, lower income elders often have a difficult time securing and maintaining decent, affordable housing. High housing costs are the main problem - and a substantial number of elders pay more than what they can realistically afford for housing.

As noted in an earlier chapter, unattached elders are far more likely than those who live in families to have low incomes

Having decent, affordable housing along with adequate income and quality of health care are the cornerstones on which a secure retirement - with quality of life - is built. Considering this, various levels of government provide housing support for elders. The Canada Mortgage and Housing Corporation (CMHC) through its housing agency, for example, has a variety of programs designed to help improve housing choice and affordability for Canadian elders. It delivers these programs through a combination of social housing contributions, renovation programs, and "enabling" initiatives.

Much of the CMHC's work is done in partnership with other levels of government, as well as a variety of housing agencies and sponsor groups. While the CMHC does provide significant cash to affordable housing initiatives, a portion of its' work focuses on facilitation only. The CMHC's Canadian Centre for Public-Private Partnerships in Housing, for example, brings together the public and private sectors, not-for-profit groups and organizations, and private citizens, to facilitate the production of affordable housing without federal government subsidies.

Since its inception in 1991, the Centre has facilitated over 19,500 affordable housing projects for elders across Canada.

Between the mid-1970s and the mid-2000s, a significant amount of rental housing was built with financial support from the federal, provincial, and municipal levels of government.

In 2016, approximately 550,000 subsidized social housing units exist across Canada with close to 200,000 of these being committed to elders. Additional units for elders are also available under unilateral provincial programs.

2 - 4.10 Types of Social Housing

Public housing, non-profit housing, and co-operative housing are all operated on a "not-for-profit" basis.

Public housing is owned and managed by either provincial or municipal governments.

Non-profit "rent-geared-to-income" housing, meanwhile, is owned and managed by either municipal governments or private non-profit charitable organizations (such as churches, seniors’ organizations and ethnic or cultural groups).

This type of housing makes rents affordable for low-income households by gearing the rent paid to their income.

In rent-geared-to-income housing, eligible households are selected from waiting lists. The rent paid by the household is calculated to equal 30% of the total household income from all sources. The balance is government-subsidized.

In order to access this type of housing, elders apply directly to the local non-profit groups or agencies involved.

Co-operative housing offers some of the same advantages - to low-income elders - as non-profit housing - but with a twist. Co-operative housing is owned and controlled by the residents themselves - all of whom are voting members. Outside property owners are not involved. The residents, with an elected board of directors, govern the co-op.

Co-ops include people from a variety of economic backgrounds. Moderate and high-income residents pay the full freight, while lower income residents are subsidized - paying only 30% of their income towards rent. Once again, the government covers the balance of the rent due.

2 - 4.11 Rental Supplements

The government also works with private "for profit" organizations. Property owners sign an agreement with the government to base their rents on income - and the government then pays the owner the difference between the actual "market-based" rent and the rent paid based on income.

Elders apply directly to the proprietors or agencies that manage these units. Units of this nature are in communities throughout Canada.

2 - 5 ELDERS ON THE MOVE

Often people mistakenly assume that elders move - almost exclusively - to enter an institution. Elders move for many of the same reasons that younger adults move - their existing home no longer "fits," they want to live in a better neighbourhood, or to be closer to their family.

When elders consider a move, other issues also come into play - things like shopping, medical facilities, social contacts, as well as the availability of community resources. For some, the cost of maintaining their existing home is also a factor.

A recent Statistics Canada/CMHC survey found that the reason for moving most often cited by Canadian Seniors was to find a better quality of a dwelling.

Moves of this nature were made largely in response to the fact that their children had left home - along with a desire to own or live in a home or unit that required less effort to maintain.

Older elders (age 70 and older) were more likely - than younger elders - to move for health reasons, to access leisure activities or to be closer to family - and they were almost twice as likely to move in order to enter an institution.

Table 2 - 2 Reasons Why Elders Move

Reason for moving	Age 65+
Quality of the dwelling / unit	40%
Attraction of the dwelling	39%
Closeness to facilities and services & Services available on the premises	36%
Recreational facilities and actives	31%
Change in health or physical strength	28%
Friend/relatives live there & children or relatives live nearby	27%
Difficulty looking for a residence	20%
Wish to be with others of the same age group	21%

Source – Statistics Canada, Canada Mortgage & Housing Corporation

A recent survey conducted by the construction industry produced similar results. Based on their findings, they were able to divide elders into the following "buyer groups:"

- **"Junior Elders" (Ages 55 to 64)** – these are the "Move Down" group. They have recently become empty nesters, already having satisfied their desire for a large home that suited their lifestyle while raising their family. Most still earn an income and are looking for smaller lots, smaller homes, often bungalows, and still prefer home ownership.
- **"Intermediate Elders" (Ages 65 to 80)** – these are the "No Maintenance Dwellers" group. They no longer want to be bothered with home maintenance. Many now live on a fixed income and want to enjoy life, travel, and focus on themselves. Some may have had trouble maintaining their home either due to physical or financial changes.
- **"Senior Elders" (Ages 80+)** – these are the "Need Assistance" group. Their health has now become an issue and they are seeking personal or health care assistance. The layout of the home is not suitable for a walker or other mobility aids. They may need to sell the home for financial reasons or when one spouse requires greater personal assistance with activities of daily living.

Of course, often the decision to move is based less on age, and more on health and mobility. In yet another survey it was revealed that twenty-two percentage of Canadians over age 60 with some degree of activity limitation (e.g., being unable to walk three city blocks without taking a rest, unable to dress themselves, or unable to use the toilet without some form of assistance) had moved in the previous five years. A third of this group had relocated to new homes specifically designed to accommodate these limitations.

2 - 5.1 Moving - But Staying Close

With respect to the moves initiated by elders, there is a strong tendency for this group to stay "close to home." In a survey completed in the mid 2000's, it was found that 80% of all Canadians aged 60 and over who had moved in the previous five years, decided to relocate no more than 50 kilometres from their previous home, while many more moved no more than 10 kilometres. Only 10% of those elders surveyed have moved more than 200 kilometres.

This is not surprising. While it usually takes people about six months to become comfortable and familiar with an entirely new neighbourhood - it takes a much longer time for elders to adjust.

2 - 6 MAINSTREAM HOUSING

Many seniors can and will remain in mainstream housing. This includes those who stay in the housing they have occupied all their working lives and those who downsize to condominiums or rental apartments. Many seniors prefer to stay in their homes, especially since most are healthy enough not to need assisted care. They often already have supports in place, including neighbours, family and friends, and do not want to move far from them and into unfamiliar surroundings.

Remaining in mainstream housing is a viable option for most elders – since all housing providers are, in a sense, providing housing for seniors, if not immediately, then in the long term. Most forms of housing are adaptable as resident's age.

As the baby boomers age, we can expect to see tremendous growth in home remodelling, whereby seniors retrofit their homes to allow them to age in place and in support services for family members who provide care for their aging parents.

Many communities are made up largely of seniors aging in place. This trend, which has been referred to as Naturally Occurring Retirement Communities (NORCs), can particularly be seen in the United States in neighbourhood developments not purposely built for seniors where large concentrations of seniors now reside.

While this trend has not manifested itself in Canada to the same degree as it has in the U.S., many Canadian cities have large populations of seniors and could develop similar profiles over time.

Developers in the larger urban centres in Canada and elsewhere are starting to build and market condominium projects that appeal not only to seniors and “empty nesters,” but also to singles or young couples without children. The building format can range from mid-rise (5 to 12 storeys in major centres) to high-rise, but the common denominator is that the locations are rich in amenities and offer good transit service. There is evidence that well-located, mid-rise buildings appeal to purchasers in the 55 – 65 age range.

One explanation for the appeal of this kind of housing to seniors is that the attitude and self-image of aging baby boomers differs markedly from those of older generations of Canadians. According to some developers, many baby boomers see old age as “happening to someone else” and consciously seek out locations that emphasize “the urban experience,” rather than developments associated with seniors.

Developers in Germany, Switzerland, Sweden, Denmark and the Netherlands have been building multi-generational projects for some time. The organizations responsible for these developments take the view that senior citizens thrive in an environment where they can mix freely with people of all ages. These projects are often created in partnership between the private sector and government, faith groups or other non-profit groups. An example in Switzerland comprises five apartment buildings with 75 units each. The mix of residents includes singles, couples, families, as well as senior citizens. The environment promotes an independent living style with barrier-free development and safety features such as well-lit common areas and non-slip tiles. Services and amenities are located nearby. Walking trails link each building to a nursery school, cafeteria, garden, and recreation area.

As the proportion of seniors in the population continues to increase, developers will need to ensure that the needs of seniors are provided for in all kinds of housing, not just housing specifically marketed to seniors.

2 – 7 INDEPENDENT & ACTIVE LIFESTYLE ACCOMMODATION

A popular option for elders who do not yet require assistance with the activities of daily living is independent lifestyle accommodation. Independent living or active lifestyle accommodation is targeted to seniors at the youngest end of the seniors’ housing spectrum.

2 – 7.1 Types of Housing

This type of development often takes the form of adult lifestyle communities that frequently combine housing with recreational amenities such as golf courses, hiking trails, club houses or tennis courts. Independent living accommodation can take any number of forms, from detached homes to units within multi-storey apartment buildings. However, in most cases, the accommodation forms part of a larger seniors’ community. Just as the form of housing can vary, so too can the tenure options. Although the most common options are freehold ownership or rental, other options exist. For example, many independent living and active lifestyle projects are developed by sponsors as condominiums, or common-element condominiums where homeowners own the freehold land and the freehold buildings on the land but share one or more common elements(s), such as a road, a swimming pool, or a park.

Many independent living and active lifestyle projects are developed as for-profit equity co- operatives. Equity co-operatives are member-controlled corporations that own both the land and the building(s) in a multi-unit residential project. What sets co-operatives apart is that they are democratic communities where the residents make decisions on how the co-operative operates. The owners of an equity co-operative own shares of the corporation and a proprietary lease or right to occupy a unit within the project. Unlike a condominium, owners of an equity co-operative do not acquire a deed to a unit. The developer of an equity co-operative sees the project to completion sells the shares to the co-operative and does not retain any residual interest.

Non-share or non-profit co-operatives also exist. They differ from equity co-operatives insofar as members do not acquire an ownership stake in the corporation and cannot sell their shares. Thus, occupancy in a non-profit co-operative is like a conventional rental arrangement, although residents, as members, are expected to participate in the business and operation of the co-operative, including electing the board of directors, approving the annual budget and maintaining the development. Many non-profit co-operatives are developed by charitable or affinity groups (that is, cultural or faith-based) and, in some cases, may have some form of capital or ongoing operating subsidy provided by the government for a certain number of units. If a co-operative receives money from the government, it must operate in accordance not only with its own rules or bylaws but also with the operating agreement between the co-operative and the government funding partner. The sponsor of a non-equity co-operative will see the project to completion and typically retain an ongoing interest as a member.

2 – 7.2 Life Lease

Some projects are developed as life leases. A life lease is a legal agreement that permits the purchaser to occupy a dwelling unit for life or until the agreement is ended, in exchange for a lump-sum payment (that is, an entrance fee) and a monthly payment to cover project management fees, maintenance costs and operating expenses. Some life-lease projects require entrance fees to be paid in full when the occupant moves in; others allow for longer-term financing.

Other variations exist with respect to how entrance fees are refunded on exit (including death or change of residence), sponsor buyback provisions if the occupant moves out or dies, and the range of services provided. Sponsors of life-lease projects can be for-profit, not-for profit or charitable organizations. These organizations see the project to completion and retain an ongoing residual interest as owner/operator.

The first Canadian Life Lease model was derived from an earlier U.S. model around 1985. The first "Life Lease" project in Canada was "Fred Douglas Place" which opened in Downtown Winnipeg in 1988.

According to a Canada Mortgage and Housing Corporation report, in 2014 there were more than 300 Life Lease projects in Canada (135 in Ontario alone). All these projects were located west of Quebec. Pinning down the exact number of projects is difficult because there is no requirement that a life lease project be registered.

Life lease programs offer a variety of tax benefits. Among them:

- Non-taxable income status of the non-profit corporation
- Not-for-profit operating for the life of the project
- No risk of capital depreciation
- Lower borrowing rates via bulk mortgage financing

Programs of this nature also offer the flexibility of rental accommodation combined with the stability of ownership. Flexibility is provided by virtue of the lease, i.e. when a tenant wishes to leave a Life Lease Project, the tenant's only requirement is to give notice (usually 90 days). Life Lease residents are not required to resell the suite as in condominiums—the onus for resell lies with the Non-Profit Housing Corporation.

Mechanics are set in place to refund the tenant their original investment upon termination of the lease or to compensate them for delays.

Stability is enhanced by the characteristics inherent in operating on a Not-For-Profit basis for the life of the Project, i.e. no profit, thus no motivation to increase rents. Rental increases are incurred only in response to increases in utilities, property taxes and mortgage interest rates.

The cost of the Life Lease to the resident is the cost of construction of their suite, plus a proportionate share of the common costs such as land and common space within the complex. Since there is no "developer's profit" the non-profit organization bases the final costs needed to operate on a break-even basis plus traditionally accepted levels of contingency. Non-profit rent includes reserves for capital replacement, vacancies, and bad debt.

The Life Lease approach offers elders a wide range of additional benefits, including:

- Security of tenure by way of the Life Lease. There is no termination date (in the event of death property is returned to the estate unless there is a surviving spouse on the lease)
- Sponsor land and/or cash equity contributions that lower capital costs and can increase amenities (i.e., Endowments, donated land, buildings, etc.)
- Sharing costs with others and economies of scale (i.e., Group investment power, preferential interest rates, etc.)
- All building and grounds maintenance, administration, common costs, property taxes, debt service, building insurance, hydro, gas, sewer, and water costs are the responsibility of the non-profit organization and are included in the resident's monthly housing occupancy charge. Residents are usually only responsible for the costs of telephone, cable TV, and insurance for household contents only
- The use of common amenities, games room, exercise room, multipurpose room, lounges, solariums, landscaped grounds, and share common needs and interests with others in a community-like setting
- Feeling of belonging, as they can participate in the ongoing operations by way of representation at Resident Association and Board level

The types of dwellings available under the Life Lease umbrella are usually multi-residential units (e.g., townhouses and apartments).

2 – 7.3 Service Packages

Depending on the age of the target market, some sponsors of independent living or active lifestyle projects, especially developments that are built near an existing retirement home or long-term care facility, may offer the residents the opportunity to purchase a basic service package as an add-on to the rental or condominium fee. In an emerging trend, the sponsor of an independent living or active lifestyle project may develop and build the project as a condominium but offer a greater range of amenities than those typically offered in a conventional seniors' lifestyle community or life-lease development. Under this model, condominium owners are required, by title, to buy into a monthly service package (like a club fee) that entitles them to various services.

While this type of housing is still considered an independent living form of development, unit owners can avail themselves of enhanced amenities whenever they want to, which is generally less often than those who reside in a retirement home or other form of assisted living accommodation. Sponsors of these types of developments generally retain a residual interest in the project and generate ongoing revenues through the provision of services.

2 – 8 ASSISTED LIVING ACCOMMODATION

Seniors who need or want more personal and health care services than those available through an independent living or active lifestyle development may choose some form of assisted living accommodation.

The form and degree of care provided in different assisted living arrangements can vary. Some developments are targeted to seniors who are still independent and offer, for example, social and physical activities and other forms of recreational activity. However, most are focused on meeting daily needs, such as meal preparation, housekeeping and laundry. Other forms of assisted living place more emphasis on personal and health care services, such as bathing, grooming, dressing and taking medication. Some provinces restrict the form and amount of personal care that can be provided without a licence. In both cases, the accommodation is designed for people who require only minimal to moderate care in order to live independently, although 24-hour supervision and emergency response are customarily included.

Accommodation usually consists of rental units within an apartment building, although in some cases it can take the form of a small group residence, commonly known as co-housing. Co-housing represents a small niche market opportunity with unique characteristics. In this model, individuals come together to work with a developer. The future residents of a project contribute to the design and help shape the development. By providing equity down payments early in the development process, co-housing participants help a developer minimize risk. An added benefit is that the project is less likely to attract objectors because the future residents have a stake in the project. Freehold, condominium ownership and life leases are not typical of assisted living accommodation, as they usually require a greater level of independence.

The most common form of assisted living accommodation is the retirement residence or retirement home. Retirement residences play the most significant role in the seniors' housing industry across Canada. Most retirement residences are privately owned and operated, but some are owned and operated by municipal governments or non-profit organizations such as faith groups, seniors' organizations, service clubs and cultural groups.

The nature and extent of government regulation of assisted living accommodation, including retirement residences, varies across Canada, although in most provinces there is some form of government oversight. In British Columbia, Alberta and Saskatchewan, for example, there is extensive government involvement in the licensing and monitoring of assisted living, supportive living and personal care homes.

Most sponsors of assisted living accommodation also belong to industry associations that set minimum standards of operation and practice.

The role of faith groups and culture-specific organizations is already extensive and is likely to increase over time, as Canada's ethnically diverse population ages. Although a higher proportion of seniors than of younger Canadians are immigrants (29 per cent vs. 21 per cent), most immigrant seniors have already lived in this country for decades. At the same time, the principal countries of origin are different today from those typical in the 1970s, when 61 per cent of Canada's immigrants came from Europe. By 2006, only 16 per cent of immigrants came from Europe. Most of today's immigrants hail from Asia, the Middle East, Central and South America, the Caribbean and Africa.

A sampling of ethnically specific housing projects across the country reflects these trends. For example, on the west coast, it is common to find housing developments developed by Japanese cultural organizations. These developments may be privately financed, or they may receive some government assistance. In other parts of western Canada, there are many Ukrainian and Filipino projects. In the Greater Toronto Area, the mix of options reflects the ethno-cultural mix of the region: For example, Chinese, Finnish and Italian. Over time, however, as migration patterns continue to change, the pool of potential residents from a ethnic group may decline, and the tenants of these developments may become more diverse.

Depending on the province, residents of retirement homes and other forms of assisted living accommodation may be responsible for all or a portion of their accommodation, care and service costs, which can vary significantly from region to region.

Accommodation in most retirement residences includes bachelor, one-bedroom and two-bedroom apartments, although the size of the suites, the number of common areas and the amenities available can vary widely. While most feature some form of dining room and common area or lounge, those targeting affluent seniors may resemble luxury hotels and feature gift shops, beauty salons, chapels, libraries, gardens, computer rooms, swimming pools and rooms for special events.

Another type of housing that can be developed for seniors is supportive housing. Supportive housing helps seniors and others who need additional services, such as individuals with disabilities, in their daily living by combining a physical environment that is specifically designed to be safe, secure, enabling and home-like with support services such as personal care, meals, housekeeping, and social and recreational activities. This arrangement allows residents to maximize their independence, privacy, dignity and decision-making abilities. Supportive housing can be developed in many forms depending on the types and level of services to be provided, the project size desired, the types of accommodation preferred, the types of tenure wanted and the types of sponsorship available. Services can be provided through a combination of on-site and off-site arrangements and can be made available to both residents and other older people living in the surrounding neighbourhood.

Highly service-enriched supportive housing can be an alternative to unnecessarily accommodating people in a nursing home or long-term care facility.

Supportive housing may be developed by the for-profit, not-for-profit or public sector — or through partnerships between these sectors. It can be made available in a range of tenure types, such as rental, leasehold, condominium and life lease. It is also possible to combine different tenure types in individual projects. Several provinces have developed their own definitions of supportive housing that is eligible for public funding.

2 – 8.1 The Best of Both Worlds

Assisted living accommodation is often viewed as the best of both worlds. Residents have as much independence as they want with the knowledge that personal care and support services are available if they need them.

These services available can provide residents with assistance with basic ADLs (activities of daily living) such as bathing, grooming, dressing, and more. Assisted living facilities may also offer medication assistance and/or reminders. Assisted living communities differ from nursing homes in that they do not offer complex medical services.

The physical environment of an assisted living is often more appealing to both potential residents and their families. These communities offer a more home-like atmosphere than what is available in a nursing home.

2 – 8.2 Trends in Assisted Living

During the past decade, there have been dramatic changes in the typical retirement home/assisted living facility in Canada. Many are now catering to a new generation of "private pay" retirees – those with comfortable personal income – who want even more amenities and choice.

Your grandmother's retirement home is not the retirement home of the future. We are amid a transformation of the seniors housing industry. Demographics are driving the change. In April 2013, RBC Dominion Securities Inc. forecast "potential nationwide demand for an additional 4,000 to 5,000 private-pay suites annually for the next 15 years." RBC analysts singled out boomers as "likely to be demanding in terms of their desire for hotel or resort-like settings and higher levels of service."

Many homes now offer high-end finishes, granite and hardwood, spas, and bowling alleys. The food experience is often a major focus with chef-prepared meals and private dining rooms for entertaining family and guests. The demand for choice is reshaping the landscape.

New product offerings are designed to attract the more independent and healthier senior. As noted, creating a home-like atmosphere is also a major focus.

As noted above, assisted living residents are usually for elders who have had a slight decline in health in some way and need assistance performing one or more activities of daily living (ADLs).

Elders who would like to live in a social environment with little responsibilities and a place where care is easily accessible whenever the elder may need it. Statistically, the most common resident of an assisted living community is a female in her mid-eighties.

Many assisted living communities allow the resident to age in place. Communities can do this because many have care available on-site, and if they do not, they contract with local healthcare providers so that the resident can stay at the community as his or her level of care increases. This care is paid for on top of the monthly rent and varies depending on the amount of care needed.

2 - 8.3 Common Names

Residential Care Facilities for the Elderly, Board and Care, Community Based Retirement Facilities, Personal Care, Adult Living Facilities, Adult Foster Care, Adult Homes, Congregate Care, Adult Congregate Living Care, Domiciliary Care, Supportive Care, Enhanced Care, Sheltered Housing, and Elder Care Homes.

The generic term used throughout the country is "Assisted Living" and you may see it abbreviated to ALF (for Assisted Living Facility). Canada has regulations governing Assisted Living Facilities and most require some type of licensure and/or certification.

2 - 8.4 Services Available

Assisted Living Facilities are designed to provide a special combination of personalized care, supportive services, and health-related services. They are also designed to minimize the need to relocate by accommodating an individual's changing needs and preferences. Residents are encouraged to function as independently as possible with some assistance from staff. Twenty-four hours a day support service is available to meet the planned and unplanned needs of the residents.

Although the types of services and level of care do vary, most facilities aid with bathing, dressing, grooming, personal hygiene, ambulating, and monitoring of medications and dietary intake. Additionally, meals, transportation, laundry, and housekeeping are usually provided; however, the amount of health care provided varies widely among facilities. Although some facilities have medical care centres, the health care offered is not as intense as that of the care in a nursing home.

Assisted living is appropriate for someone who is too frail to live at home but does not require constant skilled care.

Therefore, this housing option exists to bridge the gap between independent living and skilled care in nursing homes. Assisted living is often deemed necessary when the person in question is sometimes confused or experiencing memory problems.

Caring for residents with Alzheimer's or other dementia and disabilities is possible when a facility's design and philosophy is conducive to assuring their safety and autonomy.

Most assisted living residences develop a care or service plan custom tailored for residents upon their admission. These plans detail the personal needs required by the resident and the commitment of the facility to deliver such services.

The plan is updated as needed to address changes in the resident's condition to assure the resident receives the appropriate care.

Social, educational, and recreational activities are often offered like those in independent living and retirement communities. As an individual's health decline however, this type of setting may no longer be appropriate, and another setting may need to be considered.

2 - 8.5 Housing Arrangements

As noted above, Assisted Living Facilities come in all shapes and sizes, from single-family homes with only a few residents, to large communities with hundreds of residents. They can be free standing, part of a retirement community, continuing care community, or independent housing, or affiliated with a nursing home.

Choices vary from studio, single, or double rooms, to suites or apartments, and are usually within a multi-unit residential setting. Residents may have their own living quarters, or they may choose to share their quarters with a spouse or roommate.

2 – 8.6 Payment Methods

Most residents generally pay the cost for care from their own financial resources. They sign a residency agreement as they would when renting an apartment and likewise, the rent varies according to the size and location of living quarters, as well as amenities and services available. In addition, the monthly rent may cover all services, or there may be charges for services above the monthly fee when used. These residences may be operated as either not-for-profit or for-profit.

2 - 9 HOME SAFETY

The previous two segments looked at lifestyle and assisted living communities. As attractive as these types of housing arrangement may be, the fact of the matter is that most elders have a very strong desire to remain in their own homes and maintain a significant degree of independence. Unfortunately, the onset of numerous mobility and sensory challenges can turn their home environment into a dangerous minefield.

In the case of elders who are determined to remain in their own homes, a careful review of their homes - with an eye to removing the risks - is in order.

Some of the questions that need to be asked follow:

Entrance Way: Is the key easy to turn, or does the elder have to struggle? Is there a peephole or window to view visitors before entry? Is the lock secure? Is there a railing present for support? Does the elder have an alarm system?

If so, many alarm systems are rigged on 15-second response times.

In other words, the person entering the home has 15–30 seconds to get to the control panel and decode the alarm. If an elder's mobility is impaired, 15–30 seconds may not be long enough for him or her to reach the panel. Moreover, he or she may risk potential injury to make it to the panel before the time expires.

Living areas: Are the walkways clean and uncluttered? Can the elder get through the doorways easily? Is it possible to sit down in, and get up from, sofas and chairs easily, or is it a struggle? Many chairs are so low or soft that an elder could lose his or her balance while attempting to sit down or stand up.

Are there any stray electrical cords stretching across the floors (a risk for everyone)? How easy is it to turn on lights and the television? Is there a phone within easy access to the sitting area? Are there a lot of throw rugs? They tend to bunch up and could cause an elder to trip. If the home has stairs, is the handrail secure, are the stairs and stairwell well lit? Are stair carpets secure and are the stairs completely clear of objects and obstacles?

How easy is it to open and close the windows? Are they rigged to the home alarm system, and if so, is there a control box or panel located nearby? Some windows hooked up to alarm systems have separate control boxes located underneath.

Kitchen: Do the appliances work well? Can the elder reach the faucets on the kitchen sink? Can he or she reach the microwave, oven door, controls on the stove, as well as the refrigerator and freezer in order to be self-sufficient with meal preparation? Are the dishes, glasses and silverware placed in a spot where they may be reached easily? Consider plastic ones to prevent any mishaps. Are there any sharp objects lying about that could cause injury?

Are the electric sockets within easy reach so that the elder can plug in a toaster, etc.? Does the elder have any flammable lying in potentially dangerous areas? Napkins, paper towels, and dish rags should be moved away from the stove area.

Does the elder have a throw rug on the floor, which could shift, and cause them to trip? Is it easy to carry food from the counter to the table, and do the chairs push away from the table easily?

Bedroom: How easy is it to get in and out of bed? High beds are not easy for anyone, let alone someone with physical limitations. Is there a phone by the bedside for use in the event of an emergency?

Where is the bathroom in relation to the bed, and is there a clear path to the doorway of the bathroom, as well as the doorway leaving the bedroom? How close is the light switch or lamp to the bed?

Where the dresser is located and can the elder reach his or her dresser drawers easily?

Bathrooms: In all bathrooms, you will want to ensure that the elder can move in and out of the tub easily and without risk. Install *no-skid* strips or a rubber bath mat on the tub floor and place another one beside the tub.

Depending upon the elder's mobility, you may want to avoid giving him or her access to a shower with a glass door. Can the elder reach his or her personal items in the bathroom? Is it time to consider installing hand bars and/or a seat in the shower?

Can the elder reach the electrical outlets in the bathroom? Are the faucets in both the tub and sinks conveniently located?

Overall: Make sure that multiple smoke detectors are in place, and that the batteries are replaced on a regular schedule. You may want to consider purchasing a carbon monoxide detector, as well. Check your electrical cords (for frays and/or exposed wires) and outlets, and make sure all light bulbs are in good working order. Remove throw rugs if necessary - they are *an accident waiting to happen*.

Check all appliances to make sure they are working. List emergency phone numbers alongside every phone in the house. If the elder leaves the house to run errands or check the mailbox, make sure that the paths leading outdoors are clear. It may be a good idea to equip the elder with a cell phone. In addition, if he or she is taking any medication, it should be kept in a consistent spot so there is no risk of a mix-up. Also, dosages should be written down on a sheet of paper and posted near the medications.

2 - 9.1 Home Renovations

Often, with some renovations, an elder can remain in his or her own home for life. The most common adjustments are bathroom modifications, followed by street-level entrances, extra handrails, and in some cases, a lift device. As Canada ages, there will be an increase in the demand for special adaptations to existing homes - and many new homes will be built with these features as well. In the future, it is also likely that increased safety and accessibility will become important selling features.

Finding reliable trades people to do renovations is often best accomplished via word of mouth. Ask friends and acquaintances for recommendations and be sure to get price quotes from at least three potential contractors.

The following material will provide you with a laundry list of ideas when it comes to the kinds of renovations that might make sense.

2 - 9.2 Electrical Outlets

Adding more electrical outlets in convenient locations can improve the safety of an elder's home. Several well-placed outlets will help prevent overloading others or having to run electrical cords across areas where they become a hazard. Extension cords should never be used on a permanent basis since they present both a tripping and a fire hazard.

2 - 9.3 Lighting

It is important to have plenty of well-positioned and well-diffused lighting. It is best to avoid lighting that creates glare or shadows. Extra lighting should be installed on stairways and other areas where specific tasks are done (e.g., over the bathroom sink, in the kitchen, and in any other work areas).

In the case of older homes, the wiring may need to be updated. When changing lighting and wiring, it is also a good idea to consider the location of the switches - ensuring that they are placed in the most convenient location. There should, for example, always be a switch near the entrance to a room and at both the top and bottom of a flight of stairs.

Lowering the light switches is also a great idea to accommodate an elder who is in a wheelchair. The type of switch is another important thing to consider. Rocker panel switches are best since they are easy to use.

Dimmer switches can be useful as well. They allow you to leave certain lights on low for safety reasons (e.g., between the bedroom and bathroom).

2 - 9.4 Doors

If a door is to be replaced, check the height of the door sill or threshold. It should be no more than 1/2" (13 mm) in height. It may be a good idea to reduce or remove the door-sill, because any uneven surfaces can lead to a trip or a fall. It is also advisable to widen doorways so that they can accommodate wheelchairs.

Consider replacing standard doorknobs with lever handles, which are easier to use. If possible, fix the levers such that they are angled away from the door opening to ensure they do not catch on clothing. Also, consider the advantages of sliding or swinging doors, and doors that open outward.

2 - 9.5 Stairs

The backs of stairs should be closed in. There should be firmly anchored handrails on both sides of the stairway, which extend beyond the top and bottom steps. The handrail should also be mounted far enough out from the wall to allow for a solid grip. In addition, the stairway should be well lit, and the steps should have a non-slip surface.

2 - 9.6 Flooring

If floors are to be replaced, use non-glare, slip-resistant flooring material. A hard floor surface or tight pile carpeting is best. Consider using the same floor surface over different areas in order to eliminate uneven surfaces.

2 - 9.7 Kitchen

For efficiency and convenience in the kitchen, consider adding lower level shelves, between the counter top and cupboard level. Also consider adding sliding shelves in lower shelving units, and lazy-susan's in cupboard corners - both of which allow kitchen items to be within easy reach. A pantry with low-level shelves may also be worth considering.

If you plan to replace your kitchen taps, lever-type or control-arm-type faucet handles are the best, because they are the easiest to use.

2 - 9.8 Bathroom

Taps with lever faucet handles are easier to use. Installing grab bars around the shower or bathtub and beside the toilet can help prevent falls in the bathroom. Portable bath seats are available, but you may want to consider building in a fold-down shower seat.

If you do choose this option, make sure that the shower controls are easy to reach and operate for anyone using the shower seat. A handheld showerhead is more convenient to use than a traditional showerhead.

2 - 9.9 Closet Space

The closet is one area where useful and relatively simple renovations can be made with ease. Consider installing lights in all closets. Adjustable and pull out shelves and clothing racks are convenient. The clothes bar and shelf could also be lowered, making them easier to reach.

2 - 9.10 Locks and Latches

Door locks in bathrooms must have an emergency release. Locks and latches should have large, easily manipulated knobs or levers. The market now has models that offer both safety and security (e.g., push-button or card-access locks).

2 - 9.11 New Community Service - 211

When it comes to elder safety, a major new initiative is in the works. Just as you now dial 911 for emergency services, in the future, you will be able to dial 211 anywhere in the United States or Canada to get access to community health and human services information. The information available will include such things as adult day care, congregate meals, Meals on Wheels, respite care, home health care, transportation, and homemaker services.

The "211" initiative was started in Atlanta and it is spreading across both the United States and Canada. Organizations that lead the way on this initiative include the United Way and the Alliance of Information and Referral Systems.

In the U.S., the Federal Communications Commission (FCC) approved the designation of the "211" phone number for this purpose several years ago, and "211" initiatives are now underway in every state.

The Canadian Radio-television and Telecommunications Commission (CRTC) has assigned access number 211 to a new, toll free service that will supply information and referrals about community, social, health, and government services. The United Way of Canada and several other agencies brought the application for three-digit dialling access to the Commission several years ago. In its bid for the access number, many parties, including municipalities, regional and provincial governments, local distress centres, Kids Help Phone, volunteer centres and community medical services, supported the United Way group. "Canadians gain in two ways," says David Colville, chairman of the CRTC. "First, the 211 service will help the public find the right person or agency much faster. Second, we now have guidelines in place for allocating the three-digit access numbers."

The 211 programs will greatly simplify the process of finding services to help elders. Phone calls are answered by personnel trained to help assess needs, identify services which are available, and route callers to the appropriate organizations.

As of 2018, the 211 service is available to approximately 75% of Canadians, or about 26 million people. Some rural areas and the provinces of Prince Edward Island and Newfoundland (as well as the Northwest and Yukon territories) are still without service.

2 - 10 FALLS

According to the Public Health Agency of Canada falls account for more than half of all injuries among Canadians 65 years and over. One third of community-dwelling Canadian senior’s experience one fall each year and half of those will fall more than once. The likelihood of dying from a fall-related injury increases with age; among seniors, 20% of deaths related to injury can be traced back to a fall.

Falls account for 34% of all injury-related hospital admissions and 85% of seniors' injury-related hospitalizations, making this the leading cause of injury-related admissions for seniors. Forty percent of seniors' falls result in hip fractures and half of those who break their hips will never recover fully functioning; women sustain 75–80% of all hip fractures and one in five older adults will die within 12 months of suffering a hip fracture. Apart from personal suffering, loss of independence and lower quality of life, the costs of seniors' injuries to the health system are enormous—approximately $2 billion annually is spent on direct health care costs. Seniors' falls are also responsible for 40% of admissions to nursing homes.

2 - 10.1 Preventing Falls

Falls are among the most preventable of all risks. To reduce the risk of falling, elders can make use of the following suggestions. It may even make sense to print and post a list of this nature in a convenient spot - for easy reference.

- Be physically active every day, and exercise for strength and balance
- Eat regular, well-balanced meals
- Keep the home and garden free of hazards
- Install aids around the house such as grab bars, railings, and non-slip surfaces
- Keep pathways and steps free of ice, snow, newspapers, and leaves
- Plan outings to allow plenty of time—never rush
- Use aids for walking, balancing, hearing, and seeing
- Always remove reading glasses when walking
- Ask for assistance with any heavy work
- Manage and monitor medications properly, and check with a doctor or pharmacist when unsure

Most falls occur at home—especially in the kitchen, on the stairs, and in the bathroom. The following material provides some ideas on how to make the inside and the outside of an elder’s home a safer place.

2 - 10.2 When Leaving Home

- Take all the time necessary
- Wear appropriate footwear to prevent slipping, and avoid laces that may come undone
- Use a walking aid if needed
- Walk slowly and carefully—be alert to sidewalk cracks, obstacles, slopes, slippery surfaces, and other hazards

- Do not become loaded down with packages; take advantage of home delivery or use a pushcart (which can also act as a walking aid)
- Be a defensive walker—watch carefully for traffic, bicycles, and roller blades
- Plan your trips to avoid rush hour, darkness, or bad weather

2 - 10.3 In the Kitchen

- Eliminate throw rugs
- Have everything within reach so that there is no need to climb. If climbing is necessary, use a stable step stool with a safety rail
- Wipe up any spills immediately to prevent slipping

2 - 10.4 On the Stairs

- Have handrails on both sides of the stairs
- Make sure stairs are properly lit
- Don't leave anything on the stairs

2 - 10.5 In the Bathroom

- Install a grab bar and non-slip mat in the tub and shower
- Use a non-skid bath mat
- Install a night-light in the hallway and bathroom
- Wipe up moisture or spills immediately

2 - 10.6 In the Living Room

- Leave generous space to move safely around furniture
- Make sure electrical cords are out of the way
- Ensure furniture and lamps are steady and stable

2 - 10.7 In the Walkways and Entrances

- Have a small bench in the entryway to make it easy to put on and remove boots
- Make sure the steps and walkways are free of ice, snow, newspapers, or wet leaves
- Have a handrail installed along the front walkway if necessary

2 - 10.8 In the Garden

- Put the hose away in a secure area when not in use
- Make sure rakes and shovels are safely put away when not in use
- Wear shoes that support and stabilize
- Keep garden tools handy in a pail or in a gardening apron
- Use a kneeling pad while weeding. Rise slowly when done
- Do not walk on wet grass; keep the yard, pathways, and steps free of leaves and twigs

2 - 10.9 Other Precautions

- Do not try to do tasks that are too strenuous or potentially dangerous. Find a volunteer – such as a friend, neighbour, relative, or building maintenance staff to help with the heavy work
- Take care not to trip on a pet (or a grandchild's toy!) - always check the floor, the stairs, and the hallway
- Turn the lights on while moving through the house
- Take off reading glasses when finished reading
- Use a cane or walking aid inside the house if necessary
- Do not rush to the phone: if there is an answering service, callers will leave a message; if not, they will call back

Finally, elders should know that they have the right to be safe. If there are any hazards or unsafe conditions in the neighbourhood, the proper authorities (i.e. Municipality, apartment owner, elders' centre, and store staff) should be notified.

2 - 10.10 Reducing the Risks

As people get older, their bodies change and can become more susceptible to falls. Certain risks can be eliminated, and others considerably reduced, by simple prevention measures.

- ***Physical fitness -*** Given that daily routines become less physically demanding as people age, one can experience reduced physical fitness, increasing the risk of falls. Maintaining or regaining physical fitness is the most effective fall prevention measure. All forms of exercise, formal and informal, can help maintain the strength and vitality that will protect people from injury.
- ***Balance*** - Balance is an important element of fitness. Tai Chi, yoga, and dancing are all exercises that increase balance and steadiness—proof that keeping fit can be fun! Other factors can affect balance, including improper use of eyeglasses, misuse or disuse of assistive devices, and certain medications.

Elders should make sure they are aware of these dangers. They should exercise for balance and use devices and medications appropriately

- ***Nutrition*** - Regular healthy meals help keep up strength and vitality. Consult Canada's Food Guide to ensure optimum nutrition. If the elder does not enjoy preparing meals by themselves, they could occasionally invite friends over, eat out, or develop a routine that makes them look forward to their meals, such as a candle lit table, a special treat, etc.

2 - 10.11 Use of Medications

Be aware that medications can sometimes cause dizziness or other side effects. Always read instructions and warnings carefully. Elders should consult their doctor, pharmacist, or health care worker about the possible side effects of their prescription or any over-the counter medications used. In addition, remember that medication and alcohol can be a dangerous combination!

2 - 11 HOME SUPPORT

For Canadian elders who have a strong desire to remain in their homes if is possible, there is a lot of support available - from family, friends and a wide variety of social services.

As noted earlier, the number of seniors living with relatives or non-relatives in a private dwelling has increased in the past decade. And the total number of seniors living alone has also increased to over 1.5 million from one million (in 2001).

When it comes to a need for services, the most exposed group is elders who live alone. Managing their own affairs independently can become extremely difficult - particularly as they begin to experience physical decline. This challenge can be particularly trying for elders with limited incomes, and elders who are far away from family.

Women aged 65 and older are twice as likely to live alone, than men, mainly because the women had higher life expectancies and older partners and were more likely than men to be widowed.

2 - 11.1 Social and Family Support

Most Canadian elders can look after themselves and their homes – but the majority does get some help with household work and other personal chores. In total, about one in four Canadian seniors, close to 1.5 million people, receive home care such as housework and transportation.

More than one half of seniors receiving home care said that they relied on family, friends and neighbours for the support.

As noted in an earlier chapter, this figure is, however, likely underestimated since seniors might not have reported some informal care (such as that received from a spouse).

2 – 11.2 Defining Home Care

In Canada, home care has been generally defined as an array of services which enables clients, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives.

Home care may be delivered under numerous organizational structures, and similarly numerous funding and client payment mechanisms. It may address needs specifically associated with a medical diagnosis (e.g., diabetes therapy), and/or may compensate for functional deficits in the activities of daily living (e.g., bathing, cleaning, and/or food preparation). Home care is a health program, with health broadly defined. To be effective, home care may have to provide services, which in other contexts might be defined as social or educational services (e.g., home maintenance, volunteer visits, etc.).

Home care may be appropriate for people with minor health problems and disabilities, or for those who are acutely ill, requiring intensive and sophisticated services and equipment. There are no upper or lower limits on the age at which home care may be required, although as in other segments of the health system, utilization tends to increase with age.

"Home care can alleviate demands for hospitalization, it can reduce readmissions to the hospital and as well it can decrease the likelihood of institutionalization," said analyst Melanie Hoover, with Statistics Canada in Ottawa.

There is evidence that expanding home-care services and support for caregivers saves the healthcare system money in the long term, agreed Prof. Wendy Young, Canada Research Chair in Healthy Aging at Memorial University of Newfoundland.

"How many people understand that granny getting her housework done actually saves the healthcare system an incredible amount of money? If she cannot get her housework done, then she ends up being admitted to a nursing home."

Statistics Canada researchers asked people 65 and older about their use of formal or professional assistance like Meals on Wheels, and informal home care from family, friends or neighbours in the previous year.

Among those who had received home care, the most common types were:

- Housework, including home maintenance: 18 percent.
- Transportation, including trips to the doctor or for shopping: 15 percent.
- Meal preparation: 10 percent.

2 - 11.3 Unmet Needs for Professional Home Care

In a recent survey close to 180,000 seniors reported that they had at least one unmet need for professional home care services. Close to two-thirds (63%) of seniors with unmet needs for formal care attributed them to personal circumstances, such as inability to pay; 24% cited features of the health care system, including lack of service availability; and the remaining 13% mentioned a combination of both. Research shows that unmet needs for assistance are associated with negative consequences including inability to prepare food for oneself, injuries, depression and reduced morale, higher hospitalization rates, and increased risks of falls, institutionalization, and premature death.

Housework and personal care such as assistance with eating, dressing or bathing were the two most common unmet needs.

Among those with severe disability, about 10 percent had unmet needs compared with one percent among those with no or mild disability.

2 – 11.4 Purpose of Home Care

Home care programs are designed to provide:

- Substitute functions for services provided by hospitals and long-term care facilities
- A maintenance function that allows clients to remain independent in an existing or new location
- A preventative function, which invests in client service and monitoring. This creates an additional short-run cost - but it reduces overall costs in the long run

2 - 11.5 Provincial variation

All provinces and territories have developed different definitions of home care specific to their home care programs. Due to the diversity in range and orientation (e.g. clinical approach and client profile) of services among programs, it is possible that people, when referring to home care programs in their respective provinces and territories, could be talking about different sets of services and clients.

It is also important to note that the emphasis in home care has changed somewhat in recent years.

Post-acute or hospital substitution services have taken on greater emphasis relative to maintenance and prevention services than was the case in the past. With hospital reforms such as consolidation, shorter lengths of hospital stays, day surgery, etc., the need for heavier acute care in the home and community has increased.

Having said this, acute home care is still regarded by provinces and territories as only one of several components of home care services. Diverse clients have diverse needs.

Long-term home care clients such as the frail elderly, still have access to health care, personal care, homemaking, and other social support services in the home setting (but not limited to this setting) to meet their needs and those of their family and volunteer caregivers.

2 – 11.6 Jurisdiction for Home Care Services

As noted, the jurisdictional responsibility for providing home care services rests with the provinces and territories. Publicly funded home care programs exist in every province and territory in Canada. Since each program has undergone its own unique development in response to community needs, service delivery varies across the country.

This diversity of home care programs is both a strength and a limitation. While individual programs allow for more specific and local responses to address needs, the lack of common terminology, standards for service delivery and information collection across jurisdictions has limited the ability of individual jurisdictions to benefit from the development of collective initiatives across the country. Some of the potential benefits for all jurisdictions of collective work include enhanced research activity, examination of the cost-effectiveness of interventions, and enhanced information systems to support improved management and policy decision-making.

Home care is included in the federal Canada Health Act as an extended health care service. However, home care services are not publicly insured in the same way as hospital and physician services. Provinces and territories provide and publicly fund home care services at their own discretion.

The Canada Health Act sets out the conditions for federal transfer payments for health under the Canada Health and Social Transfer (CHST). By virtue of the mention of home care in the Canada Health Act, the federal government includes financial support for home care as part of CHST payments intended for health care services in the provinces and territories.

From 1977 to 1996, under the previous Established Programs Financing arrangements, the federal government provided direct per capita cash transfers to the provinces and territories for extended health care services, one of which is home care. However, in recent years, the focus of the federal approach has been assistance to home care consumers through tax credits and deductions (e.g., the Disability, Infirm Dependent, Medical Expense, and Caregiver tax credits).

2 – 11.7 Home Care Agencies

- There are approximately 600 agencies in Canada providing home care services
- 93% of these agencies receive some public funds
- 51% receive all their funding from public sources

- 67.1% of service providers are independent agencies, with the remainder being branches or franchises of large national or multinational organizations such as the Victorian Order of Nurses, Drake International, Extendicare, and We Care, or offices of provincial or regional health organizations
- Most agencies (74.3%) provide services other than home care, such as child and adult protection, education and wellness training, medical services, medical supplies and equipment, visitation, and security services
- There is a great range in the size of home care organizations; the median number of staff is 42 and the median number of clients served is 1,475

2 - 12 ADULT DAY CARE CENTRES

An Adult Day Care Program provides supervised individual programming in a group setting. As is the case with home care, programs of this nature can help an elder to remain in their own home for as long as possible.

Adult Day Care programs provide social, recreational, intellectual and physical activities that are designed to help the participant to achieve and maintain a high level of functioning, prevent premature institutionalization, and provide respite and support to caregivers. Service components include a hot nutritious meal, refreshments, medication reminders, and assistance with the activities of daily living. In addition to providing respite, these programs can also supply caregivers with information and support.

2 - 12.1 Eligibility

Elders who live on their own or with families, and who do not yet require 24-hour "nursing home" style care, are eligible to attend Adult Day Care. Many participants have a physical or cognitive disability (e.g. Heart disease or stroke, arthritis, dementia, Alzheimer's disease, etc.).

As a result, they have become socially isolated and need increased opportunities to get active and meet new people.

In some cases, adults under the age of 50 with special needs or limitations may also be considered for admission to the program.

Qualifying for an Adult Day Care program varies from province to province. In Ontario, for example, a request usually must be made to the local Community Care Access Centre (CCAC). A family member, a physician or anyone from a "community support team" can make this request. Once requested, the elder's name will be added to the CCAC waiting list.

The CCAC will then contact the elder and complete an assessment to determine eligibility and suitability.

When a space becomes available, the elder along with a friend or family member will be invited to the facility for a visit. At the visit, the elder will be asked to sign a Participation Agreement and his or her first day can be booked.

The number of days an elder attends can vary from 1-5 days a week. This is determined in partnership with the CCAC based on program space and individual needs. Most participants start with one day a week and can increase this after four weeks of participation.

2 - 12.2 Daily Activities

The Day Program offered by Adult Day Care centres provides a wide range of therapeutic, physical, recreational, social, and mentally stimulating activities. Activities like:

- Crafts & woodworking
- Special group events every month
- Fitness & movement therapy
- Bingo & other popular games
- Gardening & outdoor appreciation
- Wellness promotion
- Chapel (various denominations)
- Beauty Parlour & Barber Services
- Tuck Shop
- Library (Large Print books available)
- Income Tax Services (also available to elders in the community)

2 - 13 HOME ADAPTATION

Earlier we detailed a wide variety of the home renovations - big and small - that could be used to help elders live in their own homes even in the face of significant physical and cognitive decline. Some of the large renovations can be extremely expensive.

Fortunately, several programs, offered through the Canadian Mortgage and Housing Corporation (CMHC) can be of assistance. These programs - mostly designed for low and moderate income elders - are designed to help bring substandard housing to minimum health and safety levels, to make homes accessible to persons with disabilities, and to make emergency repairs required for the safe occupancy of homes in rural and remote communities.

CMHC also undertakes a broad range of research and information transfer initiatives related to elder housing which are designed to encourage innovation in a variety of areas including community planning, the development of new types of housing options, new financing options and types of tenure to improve housing affordability. The implementation of innovative design concepts and the use of new technology and home adaptations to improve comfort, safety, and security are also researched.

2 - 13.1 Maximizing Housing Choices

Older people as a group tend to experience sensory impairments or reductions. Also possible are mobility limitations ranging from weakness because of frailty or illness, through stiff joints and bad backs, tremors and loss of coordination, to situations requiring the use of a walking aid or wheelchair.

Environmental design can compensate for many of these losses. Wall and floor surfaces that reduce reflected sound would help someone with impaired hearing carry on a conversation. Strong and well-diffused lighting can improve depth perception and minimize shadows, helping a person see that next step more clearly. Furniture arrangements should allow people to sit close enough to see and hear each other comfortably. One of the more promising approaches to making homes accessible to all is "barrier-free" design.

2 - 13.2 Barrier-Free Design

The design is said to be barrier-free when an environment contains no architectural, design, or physiological features that might prevent anyone, able-bodied or impaired, from using the environment fully to his or her abilities.

It is useful to examine the implications of this definition from two points of view: existing environments, and those still on the drawing board. Most people have seen the ramps, wider parking spaces, and amplifying telephones that are among the most obvious attempts to make the environment more accessible to people with functional impairments. Accessibility modifications to an existing home can range from buying a few simple aids and devices for daily living to a full retrofit job with ramps and lifts at changes of level. Even a remodelled kitchen and bathroom - depending on the degree of functional capability of the elder - may be required.

When a building is in the conceptual stage however, the opportunity exists to create good, accessible design before barriers are built. There can be no excuse for designing a sunken living room, a tiny bathroom, or narrow doorways. Barrier-free design is founded on the principle of promoting the continuing utilization and considers the possibility of future changes in functional capacity.

The Design Workbook put out by CMHC reflects this by describing design criteria that will suit residents with a range of functional ability, so that all individuals, regardless of strength or mobility, will always find the environment safe and negotiable.

2 - 13.3 Home Adaptation Assistance

For years, the Canada Mortgage and Housing Corporation has provided home renovation assistance to low income Canadians, low income Canadians with disabilities and Canadian elders under a variety of programs. However, much of the responsibility for the programs described below has now been assumed by individual jurisdictions (with the notable exception of the Yukon Territory).

On July 4, 2011, the federal, provincial and territorial governments agreed to a new framework under which to deliver benefits to Canadians in housing need. The new framework is called the Investment in Affordable Housing (IAH) initiative.

Under the IAH bilateral agreements, provinces and territories have greater flexibility to invest in a range of programs and initiatives in order to reduce the number of Canadians in housing need by improving access to affordable housing that is sound, suitable and sustainable.

Provinces and territories cost-match the federal investment and are responsible for program design and delivery in order to address their local housing needs and priorities.

Provinces and territories can use funding under the IAH to:

- increase the supply of affordable housing
- improve housing affordability for vulnerable Canadians
- improve and/or preserve the quality of affordable housing
- foster safe, independent living

Initiatives can include new construction, renovation, homeownership assistance, rent supplements, shelter allowances, and accommodations for victims of family violence, for example.

Initial federal funding for the new IAH program extended until 2014 – however, the economic action plan of 2013 has now extended this funding to 2019. Currently all federal funding will expire in 2033.

The following material outlines the RRAP and HASI programs currently available in the Yukon Territory and previously available in all other provinces and territories. Most provinces and territories have adopted very similar – and in many cases identical programs – to the ones described below. In some cases, only the name of the program has changed.

2 - 13.4 Homeowner RRAP

Homeowner Residential Rehabilitation Assistance Program (Homeowner RRAP) helps - to needy households - to repair, rehabilitate, or improve dwellings to bring them up to minimum standards.

For a household to qualify for this program the value of the home must be below a specified figure and household income must be below a specified ceiling (that varies based on family size and geographic location).

The home in question must be lacking facilities or require major repairs in one of five areas: structural; electrical; plumbing heating, fire safety.

The assistance provided is in the form of a loan – much of which may be forgivable (based on income, etc.).

As noted earlier, while the RRAP program described above is only currently available in Yukon – similar programs (under different names) are available in most provinces and territories.

2 - 13.5 RRAP Disabilities

The Residential Rehabilitation Assistance Program for Persons with Disabilities (RRAP Disabilities) provides financial assistance to low income Canadians with disabilities who want to make their homes more accessible. Both homeowners and landlords can qualify for assistance.

Homeowners may apply if:

- The value of their house is below a specified figure, and
- Their household income is below established ceilings (limits) based on household size and geographic area

Landlords can apply if the rent is below an established level and the unit is occupied by tenants with incomes below the income ceiling. In the case of homeowners, a loan for 100% of the cost of the renovations, up to the maximum amount allowed in his or her area, is available.

The maximum loan amounts (based on geographical area) under the original RRAP and RRAP Disabilities programs are described in the following chart. The new provincial and territorial programs offer similar or identical amounts. In southern Ontario, for example, the maximum homeowner loan (under Ontario Renovates) is now $15,000. Like the original RRAP program eligibility is based on both income and the value of one’s home.

Table 2 - 3 RRAP Loan Amounts

	Maximum Loan (Rental Units)	Maximum Loan (Homeowner)
Zone 1: Southern areas of Canada	$24,000	$16,000
Zone 2: Northern areas	$28,000	$19,000
Zone 3: Far Northern areas	$36,000	$24,000

For homeowners, the forgivable assistance available varies with household income and the cost of accessibility modifications. A repayable loan can also be provided beyond the provided forgivable assistance up to the maximum loan amount available.

For property owners, 100% loan forgiveness is available for accessibility modifications up to the maximum loan on eligible units. There are no repayable loans.

2 - 13.6 Home Adaptations for Seniors Independence (HASI)

The Home Adaptations for Seniors Independence (HASI) program helps homeowners and property owners pay for home adaptations to extend the time that low-income elders can live in their own homes independently. HASI provides a one-time, forgivable loan of up to $3,500 (2018). HASI as described is currently only available in the Yukon Territory. However most other jurisdictions offer a similar benefit with similar qualification rules. In Ontario, for example, a grant of $3,500 is available under the new Ontario Renovates program. As with HASI, this amount is available to low income elders with disabilities and qualifying landlords.

Under HASI, the loan does not have to be repaid if the homeowner agrees to continue to occupy the unit for the loan forgiveness period, which is six months. As noted in some jurisdictions the loan is now a grant. As well, in some jurisdictions the HASI program has been integrated with the former RRAP program.

Under the original HASI program and the new provincial/territorial programs, in order to qualify, the homeowner or the occupant of the rental unit must:

- Be 65 years of age or older
- Have difficulty managing daily living activities - and these difficulties must be due to aging
- Have a total household income below a specified limit for the area

In addition, the home or unit that qualifies for the loan must be the elder's permanent residence.

In order to qualify, the adaptations made must be minor items that meet the needs of elders with age-related disabilities. They could include such things as:

- Handrails in hallways and stairways
- Easy-to-reach work and storage areas in the kitchen
- Lever handles on doors
- Walk-in showers with grab bars
- Bathtubs with grab bars and seats.

All adaptations must be permanent and fixed to the dwelling.

2 - 13.7 Emergency Repair Program

The CMHC Emergency Repair Program provides grants for emergency repairs to housing in rural and remote areas. To qualify for a grant, the housing must pose a threat to the health and safety of its occupants.

2 - 14 GERIATRIC CARE MANAGEMENT

To determine what type of housing option would best suit an elder, it makes sense to consult the services of a geriatric care management team. Professional geriatric care management firms arrange for and oversee the care of elders and persons with disabilities. Case managers come from a wide variety of professional backgrounds including nursing, social work, physical therapy, and gerontology.

Case managers provide a thorough individualized assessment of each client's needs, leading to a comprehensive plan of action. Each person has different needs and resources, so case managers work closely with family members to recommend which services are best suited to their loved one.

Some of the services provided include:

- In depth assessment of needs
- Immediate crisis resolution
- Home, hospital, and nursing home visits
- Assistance with shopping, groceries, and meal preparation
- Assistance with cleaning and maintaining home and yard
- Home safety checks and modifications
- Home care management and co-ordination, including placement and supervision of home health aides, equipment, and supplies
- Regular communication with family members, whether local or long distance

- Relocation of client, permanently or temporarily, if necessary, including selection of placement and arrangements for the move
- Respite services for local caregivers
- Referrals for assistance with legal issues, financial management or supervision, filing insurance claims, etc.
- Supportive counselling to clients, spouses, and their families
- Twenty-four-hour emergency service

When evaluating a geriatric care management practice for an elder, it is very important that the proper questions be asked in order to determine the qualifications of the care manager selected. The things that should be looked for include:

- Credentials and experience
- Reputation in the community
- Rapport

2 - 14.1 Questions to Ask a Care Manager

- What is your educational and working experience with older adults and families?
- How long have you been in business? Is this a full or part-time practice?
- What licenses do you hold that permits functioning at the independent practice level? What is your hours and availability during crises?
- How do you provide backup or coverage during illness or vacation?
- What are the staff's professions and qualifications?
- Do they work under supervision?
- What are the fees for services? What services do you provide directly?
- Which services are arranged through outside providers?
- What is your role once a referral is made?

2 - 14.2 When Do Elders Need a Care Manager?

Care managers provide services to elders, family members, or adjunct professions that produce a variety of benefits, add value, and increase elder quality of life. Often situations happen which signal changes may be needed in an elder's living conditions. At other times it will be apparent that a crisis is imminent. Some of the situations that signal a change may be needed include crises, deterioration in conditions, and simple life transitions.

2 - 14.3 Crises Signals

- Frequent emergency room visits for falls, accidents, or other health events
- Reports from police, emergency medical teams, neighbours, or social services about an elder
- Depression or suicidal tendencies
- Recent loss of a spouse - accompanied by odd behaviour

2 - 14.4 Deteriorating Conditions

- A single elder is experiencing greater isolation and less stimulation from family, friends, neighbours, and social activities
- Elder is less able to care for his or her self and cannot safely be left alone
- Children are experiencing increased stress about a parent's condition
- Elders begin experiencing delusions, hallucinations, or a distorted sense of reality
- Elders or family is frustrated with the care provided or status of an elder's condition
- Elders or family is dissatisfied with the quality of a caregiver, or in-home aid's services or attitude
- Elders are unhappy with the services being provided by health care professionals or in-home caregivers, or believe they are insufficient or inappropriate
- Children are increasingly concerned about an elder's physical or mental abilities
- Pain is becoming an important issue and is affecting an elder's quality of life

2 - 14.5 Life Transitions

- Elder wants to transition to a retirement community
- Discharge arrangements need to be made for an elder from a health care facility
- Elder couple wants to live independently at home despite disabilities
- The family is considering having an elder live with one of the children
- Elders need help with end-of-life plans, advance directives, or living wills

Table 2 - 4 Sample Questions to Determine if an Elder Requires a Change in Housing

	None	Once	Several	Frequent
How often has the elder fallen in the last six months?				
How often has the elder been to the emergency room in the last six months?				
Has the elder experienced the loss of a loved one in the last year?				
How often in the last six months, has the elder felt "down" or exhibited signs of depression or melancholy?				
Does the elder need assistance bathing or dressing?				
Does the elder have trouble paying their monthly bills?				
For an elder living at home, does the elder prepare his or her own meals?				
How often does the elder miss taking prescribed medication?				
How often do family members visit with the elder?				
How often do situations arise where a family member is unable to assist the elder?				
How often has a family member lost time from work in the past six months to deal with an elder's crisis?				
How much family ‘free’ time is used to take care of an elder's needs?				

2 - 15 LONG-TERM CARE FACILITIES

In the previous sections of this chapter we focused on ways to keep an elder in their own home (whether it be a private resistance, active and independent retirement community, etc.) if possible. Often institutionalization will become a necessity.

Living in health care institutions is most common for the oldest group of elders - one of the fastest growing segments of the population.

The rate of institutionalization varies somewhat between Canadian provinces. Seniors are least likely to be institutionalized in British Columbia, where 5.4% of seniors live in institutions. In contrast, seniors are most likely to be institutionalized in Québec, Prince Edward Island, or Alberta. The statistics from Québec reflect the fact that many seniors in that province are members of and reside in religious institutions.

Long-term care homes, also known as residential continuing care facilities (Yukon), special care homes (Saskatchewan) or centres d'hébergement et de soins de longue durée (Quebec), are designed for people who can no longer live independently and require 24-hour nursing care and supervision, sometimes within a secure setting when necessary to safeguard residents with Alzheimer's or other types of dementia.

Long-term care homes offer more personal care and support than that offered by retirement residences and other forms of supportive housing. Accommodation may be shared (more than two residents in a room), semi-private or private. Units are typically furnished with a bed, chair, closets and other basic fixtures. All long-term care homes have dining rooms and common rooms, and may feature lounges, gift shops, beauty salons, chapels and outside patio or garden areas.

Long-term care homes may be built, owned and operated by various types of sponsors. Nursing homes, for example, are usually operated by private corporations. Municipal homes for the aged are publicly operated facilities owned by municipalities. Charitable homes are usually owned and operated by non-profit, charitable corporations such as faith, ethnic or cultural groups.

Long-term care homes are subject to government regulation and typically require a licence to operate. In return, sponsors receive some form of fixed government funding, calculated on a per diem basis, to provide accommodation and health care services. In most cases, residents may be expected to pay a government regulated co-payment for their accommodation, which covers basic services such as meals, housekeeping, laundry, property maintenance and administration. The exception is for residents with very low incomes who cannot afford the cost of basic accommodation. In these instances, the co-payments are generally paid by the province or health authority for the area in which the long-term care facility is located.

Long-term care homes usually offer optional services to residents for a fee. These can include cable television, telephone service and transportation. Operators of long-term care facilities can improve their profitability by providing these optional services and by attracting residents willing and able to pay a premium for semiprivate or private accommodation.

2 – 15.1 An Institutional Checklist

A variety of situations can trigger a need to relocate from the family home to an institution. Among them: the death of a spouse, a serious chronic illness, financial considerations, or family relocation. It is highly beneficial if decisions of this nature are well thought out and made at a leisurely pace.

Therefore, many medical and Caregiving professionals suggest talking about these situations long before the need arises. Careful thought and consideration will lead to a more successful transition.

Whatever the situation, as much as possible, the elder should be given the opportunity to participate. The following material focuses on some of the things that should be considered in selecting an institution.

2 – 15.2 First impressions

- Do you like the facility's location and outward appearance?
- Is the facility convenient for frequent visits by family and friends?
- Is the facility near a shopping and entertainment complex?
- Can the resident access a medical complex easily?
- Is public transportation available and accessible?
- Are you welcomed with a warm greeting from the staff?
- Do staff address residents by their names and interact with them during your tour?
- Do you notice the residents socializing with each other and do they appear content?
- Can you talk with residents about what it is like to live there and about the staff?
- Is the staff appropriately dressed, friendly, and outgoing?
- Do the staff members treat each other in a professional manner?
- Are visits with the residents encouraged and welcome at any time?
- What percentage of the apartments has been rented and is occupied?
- Is there a waiting list? If so, how long do they estimate it will be for a unit to become available?

2 – 15.3 Living Areas and Overall Accommodations

- Have the common areas and apartments been designed to allow the elder to live as easily and independently as you would like? Is the floor plan well designed and easy to follow?
- Are doorways, hallways and rooms accommodating to wheelchairs and walkers?
- Are elevators available for those unable to use stairways and handrails to aid in walking?
- Are floors of a non-skid material and carpets conducive for safe walking?
- Does the residence have good lighting, sprinklers and clearly marked exits?
- Is the residence clean, free of odours and appropriately heated or cooled?

- Are the common areas generally attractive, comfortable, and clean?
- Is there an outside courtyard or patio for residents and visitors?
- Does the residence provide ample security and is there an emergency evacuation plan?
- Are there different sizes and types of units available with optional floor plans?

- Does residence have furnished/unfurnished rooms? What is provided or what can an elder bring?
- May the elder decorate his or her own room? Is there adequate storage space?
- Is a 24-hour emergency response system accessible?
- Can the unit's door be locked?
- Are bathrooms private with handicapped accommodations for wheelchairs and walkers?
- Do all units have a telephone and cable TV and how is billing handled?
- Does the kitchen unit have a refrigerator, sink, and cooking element, and can food be kept in the elders units?
- May residents smoke in their units or are there designated public areas?

2 – 15.4 Moving In/Out Process

- Is there a written statement available of the residents' rights and responsibilities?
- Is a contractual agreement available that clearly discloses healthcare, accommodations, personal care, supportive services, all fees, as well as admission and discharge provisions?
- Find out what the payment schedule is and whether residents own or rent their unit.
- How much is the monthly fee? How often can it be increased and for what reasons? Is there a limit on the amount of increase per year? What is the history on monthly fee increases?
- Are residents required to purchase renters' insurance for personal property in their units?
- Do billing, payment and credit policies seem fair and reasonable? Can residents handle his/her finances with staff assistance if able? Must a family member/outside party be designated?
- When may a contract be terminated and what are the policies for refunds and transfers? Do dissatisfied residents have an appeal process?
- What happens if funds are depleted and full payments can no longer be made?
- Are there any government, private, or corporate programs available to help cover costs?

- What additional services are available if the resident's needs change? Is staff available to coordinate these services?

2 – 15.5 Available Health and Personal Care Services

- Can the facility provide a list of available services and are residents and families involved in developing the service agreement? Who provides these services and what are their qualifications?
- How are medical emergencies handled? Does the residence have a clearly stated procedure for responding to medical emergencies? Is there an arrangement with a nearby hospital?
- Is there a person on staff to coordinate home care visits from a nurse, physical or occupational therapist, etc., when needed on a temporary basis?
- To what extent, if any, are medical services available, and how are these services provided?
- Are housekeeping, linen service, and personal laundry included in the fees, or are they available at an additional charge? Are on-site laundry facilities available and convenient?
- Is pharmacy, barber, beautician, and/or physical therapy services offered on-site or nearby?
- Does the residence provide transportation to doctors' offices, the hairdresser, shopping, and other activities desired by residents and can it be arranged on short notice?

2 – 15.6 Social and Recreational Activities

- What kinds of group and individual recreational activities, if any, are offered? Who schedules them?
- Is there an organized activities program with a posted daily schedule of events?
- Do volunteers and family members come into the residence to participate or conduct programs?
- Does the facility schedule trips or go to other events off premises?
- Do residents participate in activities outside of the residence in the neighbouring community?
- Are the resident activity (social) areas appropriate and desirable to the prospective resident?
- Are there supplies for social activities and hobbies (games, cards, crafts, computers, gardening, etc.)?
- Are religious services held on the premises or arrangements made for nearby services? Are there fitness facilities, as well as regularly scheduled exercise classes?

2 – 15.7 Staff

- Ask about the residence's practices and philosophy regarding staffing.
- What are the hiring procedures and requirements for eligibility? Are criminal background checks, references, and certifications required?
- Is there a staff-training program in place and what does it entail?
- Is staff courteous to residents and to each other? Do they respond to requests for assistance on a timely basis?
- Is the administrator, or appropriate staff person generally available to answer questions or discuss problems, and would you be comfortable dealing with them daily?

2 – 15.8 Available Food Services

- Does the residence provide any meals? If so, how many times a day, how many days a week, and how does the menu vary from meal to meal?
- What about special diets; does a qualified dietician plan or approve menus?
- Are residents involved in menu planning and may they request special foods?
- Does dining room environment encourage residents to relax, socialize, and enjoy their food?
- Are common dining areas available? When can residents eat meals in their units?
- Are meals provided only at set times or is there some flexibility? Are snacks available?
- How many meals are included in the fee? If a resident becomes ill, is a tray service available? Can residents have guests dine with them for an additional fee? Is there a private dining room for special events and occasions, if desired?

2 – 15.9 Facility License/Certification

- If the province requires the residence to be licensed, does it have a current license displayed?
- If the province requires the administrator to be licensed or certified, does he or she have a current license or certificate?
- Is the facility a member of a trade or professional association?
- What reputation does the facility have in the community? How long has it been in business? Is it in good financial health? Does the facility follow generally accepted accounting procedures?
- If the facility is sponsored by a non-profit organization and managed under contract with a commercial firm, what are the conditions of that contract?

- Is there a resident council or organization through which residents have a means of voicing their views on the management of the community?

2 - 16 OTHER HOUSING OPTIONS

In addition to the housing options that have been discussed above, a variety of other alternatives are available.

2 - 16.1 Home Sharing

This type of arrangement will work for elders who want to remain in their own house in the community, who need security and companionship, and a little help with their home maintenance. Many elders make this arrangement on an informal basis, rather than through a home-sharing agency.

2 - 16.2 Accessory Apartments

These will work well for the adult children and their parents (especially a widowed mother) who get along and who are able to negotiate an arrangement openly and realistically. Occupants of accessory apartments are typically elderly persons who are quite independent but who need the security that "someone is there just in case."

2 - 16.3 Granny Flats/Garden Suites

These are like accessory apartments; however, they require that occupants get along and can communicate openly about their arrangements. Adult children should be ready and willing to provide support services to the parent(s).

Residents of granny flats need to be reasonably independent, to the point where they can get out on their own, or they can become very isolated, especially if their children and in-laws work outside the home all day.

2 - 16.4 Satellite Homes

These dwellings are very common in the southwest regions of Ontario. They are suitable for elders who can live in a small group setting and whose needs are for personal care to intermediate care.

2 - 16.5 Congregate Supportive Housing

This housing is suitable for a wide range of elders. It usually provides a mix of private and publicly funded support services. A large enough complex can accommodate more diverse personalities and needs than a small place. There usually is more experienced staff on site because of the mix of personalities. This type of housing has flexible services that can be increased or decreased, as residents' needs change.

2 - 16.6 Campus Models

These units can accommodate elders with no need for assistance. Usually the people who stay in this type of housing only require meals to be prepared for them, or perhaps some who need nursing care. Another important feature is that spouses at different levels of independence can live within a few metres of each other, with each one in surroundings that are suitable to their individual needs.

2 - 16.7 Summary

Whatever the choice, the housing option should be judged for its suitability in terms of the amount and flexibility of support that it can provide and the opportunities for social interaction it offers in relation to the needs and desires of elders. Other variables that must be considered are socioeconomic status and personal history. For example, some people would feel comfortable in a mobile home park while others would not.

2 - 17 CONCLUSION

People of all ages want to know that their basic life-supporting requirements are taken care of; that their housing and immediate physical environment are affordable, accessible, and comfortable, that they are safe and secure from intrusion, attack, or extremes of weather. They also want to know that they can engage in a variety of activities and make and maintain social contacts. Privacy, control, security, freedom of choice, independence and self-sufficiency are important to everyone.

Innovative housing options and technology can help older Canadians remain in their own homes as they age - but when this becomes unworkable, there are now several attractive housing alternatives available. Elder's residences are available for elders who want housing that is designed to meet their needs, health care or convenient access to recreation and leisure activities.

Factors related to aging, such as physical and sensory changes, as well as shifting social patterns and needs and altered economic circumstances all play a role in the type and design of what constitutes suitable elder housing.

Autonomy and security are considered the two benchmarks of elder housing. A door that locks, maintaining private and personal territory, usually symbolizes autonomy. Security is usually symbolized by the availability of a 24-hour emergency response system, either electronic or through social avenues.

Older elders face many important decisions when it comes to their living arrangements. Some of these decisions are voluntary, while others are necessitated because of changing health needs, finances, or the death of a spouse.

Whatever the situation, it is imperative that the elder be part of the process and is respected for whatever the choice is that they make.

2 - 18 REFERENCES

A Portrait of Seniors in Canada. 1997. Statistics Canada, Catalogue no. 89-519-XPE.

Health Canada, Falls Prevention

Housing for Older Canadians, Canada Mortgage and Housing Corporation, 2013

National Household Survey, 2011

Senior Housing Options, Help guide, 2013

Seniors 75+: Living arrangements and lifestyle. Canadian social trends, Autumn 1993.

Statistic Canada, Household Surveys Division

Statistics Canada, 2011 Census tables Statistics Canada. Catalogue 13-218-XPB; and Household Surveys Division.

Chapter 3

Caregiving in Canada

---

3 - 1 KEY OBJECTIVE OF THIS CHAPTER

Caregiving is one of the most difficult roles that most of us will ever have to assume - and yet, most of us are entirely unprepared for the challenges that it presents. This chapter is designed to offer you some perspective on the many hurdles that elders and their caregivers face. In addition, it will offer a variety of helpful hints to assist caregivers in balancing the many demands that will be placed upon them.

3 - 1.1 How Will This Objective Be Achieved?

We will take a detailed look at numerous Caregiving issues. We will discuss such topics as: caregiver requirements, stages, classifications, difficulties and demands. We will also discuss related topics like the challenges of the "Sandwich Generation," elder abuse, and the importance of "family meetings." A substantial amount of helpful information - designed to assist caregivers - will be provided as well.

At the end of the chapter we will touch on what is perhaps the most important information of all: the rewards of Caregiving.

3 - 2 INTRODUCTION

The term caregiver refers to an individual who gives care and assistance to a family member or friend who requires such help due to a chronic physical or mental health condition. Anyone who takes care of another person is a *de facto* caregiver.

Caregivers can be of any age, gender, race, religion, nationality, or ethnic background. They can be employed or unemployed. There is no formal job description for a caregiver. Caregivers may be taking care of an aging parent or spouse - sometimes it may be a disabled in-law or other family member.

Elder caregivers are generally called into service when an elder has experienced some limitation in at least one activity of daily living. No matter whom it is or what the circumstances may be, caregiving is never easy. Duties may include the physical care of a loved one and extend to such matters as financial and legal decision making.

3 - 3 ALL ABOUT CAREGIVING

Caregiving is a term that is used in the field of aging to describe a wide range of support that is provided to those elders who experience limitations in one or more tasks of daily living.

This care may involve a family member providing transportation to and from doctors' appointments or doing the shopping. Care can extend to helping with housecleaning or the provision of occasional meals in situations where elders are still, for the most part, independent and caring for themselves. This Caregiving continuum increases as the amount of care provided by family and friends increases. At the other end of the continuum, care may consist of bathing, feeding, carrying, etc. That is, coping with almost full dependency.

The types of Caregiving support provided to elder’s covers a broad spectrum of different activities. Eighty four percent of all Canadian elders receive support. The most common types of elder support (in order) were:

- help with housework and household maintenance chores
- help with transportation, grocery shopping, and banking
- checking up on them by telephone
- emotional support & personal care activities

Caregiving can become incredibly demanding. The following Caregiving timeline is what many experts have identified as the phases that a caregiver can experience.

Table 3 - 1 Phases a Caregiver Can Experience

1-18 Months	At 36 Months
• Anxious to provide best possible care for the loved one. • Maintains house, garden, and car • Attends to family relations • Keeps up appearances • Helps person with dementia through social situations. • Remains optimistic, caring, and supportive	• Stress becomes more difficult to conceal • Caregiver begins taking tranquilizers • Begins using medication for musculoskeletal pain • Sleep is continually disturbed • Caregiver becomes irritable • Less and less contact is made with others
At 24 Months	**At 48 Months**
• Begins to take medication, usually for sleep/headaches • Finds it more and more difficult to keep on top of things • Some help from family is still available	• Caregiver feels unhealthy • Finds it difficult to get up in the morning • Never feels rested • May have hypertension/colitis • Symptoms of chronic fatigue • Caregiver loses the will to take care of themselves • Is unable to manage the household • Rarely socializes with others • Feels helpless and guilty, thinks of his or herself as a failure
24-35 Months	**After 54-60 Months**
• Emotional and physical resources drained • Less and less contact with personal doctor, dentist, minister, or friends • Experiences feelings of powerlessness. • Caregiving consumes the whole day and night • Outside help dwindles away	• Chronic state of fatigue • Caregiver is in a state of ‘unwellness’ • Caregiver is unable to ask for help • Becomes isolated • Is unwilling or unable to ask for information or help

Given the demands of Caregiving - especially at the later stages - the family may not be able to provide the quality and/or quantity of care needed. They may not have the time and space required to incorporate the elder into their home life. Many families will choose not to provide direct care but to use professional services, in or out of the home.

3 - 3.1 Caregiver Duties

Most family members who help older people do not see themselves as caregivers. Yet, a caregiver is anyone who helps an older person with household chores, errands, personal care, or finances. You are a family caregiver if you help someone who cannot do or is limited from doing any number of the things for him or herself.

Anyone who performs the following functions is a caregiver:

- Drive an older family member to and from medical appointments
- Communicate with health care professionals on behalf of another
- Contact community service organizations such as Meals on Wheels, or the Alzheimer's Association
- Help arrange for home health care or hospice services
- Assist someone to pay his or her bills
- Help someone clean his or her home, or arrange for housecleaning
- Do home repairs, or arrange for someone else to do so
- Do yard work or hire someone else to do so

Caregivers also help those who need assistance in the following ways:

- Being supportive and helping the elder lead as normal a life as possible
- Supporting the recipient's independence and self-sufficiency
- Encouraging recipients to make choices that determine the course of their lives
- Reinforcing a feeling of productivity and involvement
- Help to use health care and community support
- Increasing knowledge of illness or disability
- If necessary, learning how to provide personal care; perform first aid, and CPR, lift without injury, use chair lifts, do bed transfers, and use bathroom chairs
- Helping recipients feel useful
- Bringing a positive attitude to the Caregiving relationship

3 – 4 A PROFILE OF CAREGIVERS

The Canadian General Social Survey is conducted at regular intervals. The most recent survey was done in 2012. It provides a wealth of information on various topics – including caregiving. The following material gives us an up-to-date picture of caregiving in Canada in the second decade of the 21st century.

According to the most recent Canadian General Social Survey, at some point in their lives, nearly half (46%) of Canadians aged 15 years and older will provide some type of care to a family member or friend with a long-term health condition, disability or aging needs. Over one-quarter (28%) of survey participants provided care to a chronically ill, disabled, or aging family member or friend in the 12 months preceding the survey. Providing care included, among other activities, driving someone to an appointment, preparing meals, and helping with bathing and dressing, or administering medical treatments.

While most caregivers reported providing care to one person during the survey period, assisting more than one care receiver was not uncommon. 27% of caregivers reported caring for two and 15% for three or more family members or friends with a long-term illness, disability or aging needs.

Over one-quarter of Canadians, at some point their lives, will provide care to someone who was terminally ill. Most often, caregivers providing end-of-life care were caring for their terminally ill parents.

3 – 4.1 Compassionate Care Leave

Implemented in 2004, ‘Compassionate Care leave’ can be taken, for up to twenty-eight weeks (effective January 3, 2016), by a person who must be absent from work to provide care or support to a gravely ill family member or friend at risk of dying. In 2014, 6,003 people claimed compassionate care benefits.

3 – 4.2 Most Caregivers Provide Care to Parents

Providing care most often involved helping parents. About half (48%) of caregivers reported caring for their own parents or parents in-law in 2012. Adult children were almost four times more likely to report caring for a parent than a parent-in-law, and 2.5 times more likely to report caring for their own mother than father. The latter perhaps reflects the fact that senior women often outlive their spouses and must then rely on their children for support with aging or health problems.

Caregiving was not limited to helping family members, as the second most common category of care-recipients were close friends, colleagues or neighbours at 16%. Next, grandparents represented 13% of care-recipients, while siblings and extended family members accounted for 10% and spouses for 8%.

3 – 4.3 Age-Related Needs and Cancer Most Common Conditions

In 2012, age-related needs were identified as the single most common problem requiring help from caregivers (28%). This was followed by cancer (11%), cardio-vascular disease (9%), mental illness (7%), and Alzheimer's disease and dementia (6%).

3 – 4.4 Common Caregiving Tasks

Caregiving can include a wide array of helping activities, varying in levels of intensity and degree of physical and emotional demands on the caregiver. Most Canadian caregivers reported providing transportation to their primary care receiver, making it the most frequent type of care provided in 2012. This involved transporting ill or disabled care recipients to run errands, shop, attend medical appointments or participate in social events.

In addition, about half of caregivers reported that they performed tasks inside the care recipients' home, such as preparing meals, cleaning, and laundry. Close to half of caregivers reported aiding with house maintenance or outdoor work.

The most common types of care were not always the ones most likely to be performed on a regular basis (i.e., at least once a week). For instance, even though personal care and providing medical assistance were the least common forms of care, when they were performed, these tasks were most likely to be done more regularly. Two-thirds (66%) of caregivers providing personal care did so at least once a week, as did 63% of caregivers helping with medical treatments. Furthermore, these tasks were more often done daily, with nearly one-third of caregivers providing daily personal or medical care. In comparison, half of caregivers helping with house maintenance and outdoor work reported doing these tasks on a weekly basis, with only 12% performing them daily.

Caregiving generally was not limited to one specific task or activity. Over six in ten (63%) caregivers helped their family or friends on a regular basis and most who did so, helped with a variety of tasks. More specifically, 71% of caregivers providing regular assistance helped with two or more tasks.

Emotional support often accompanied other help to the care receiver. Nearly nine in ten caregivers (88%) reported spending time with the person, talking with and listening to them, cheering them up or providing some other form of emotional support. Virtually all caregivers (96%) ensured that the ill or disabled family member or friend was okay, either by visiting or calling.

3 – 4.5 Most Caregiving Is Part Time

Along with the regularity of specific caregiving activities, the intensity of caregiving can be measured by examining the number of hours per week spent on caregiving activities. Overall, caregivers spent a median of 3 hours a week caring for an ill or disabled family member or friend. This climbed to a median of 10 hours per week for caregivers assisting a child and 14 hours for those providing care to an ill spouse. The lowest number of weekly hours involved those caring for grandparents and friends at 2 hours per week.

Most often, caregivers spent under 10 hours a week on caregiving duties. One-quarter of caregivers (26%) reported spending one hour or less per week caring for a family member or friend. Another 32% reported spending an average of 2 to 4 hours per week and 16% spent 5 to 9 hours per week on caregiving activities.

3 – 4.6 Intensive Caregiving

For some, caregiving was a large part of their life - equivalent to a full-time job. Approximately one in ten caregivers were spending 30 or more hours a week providing some form of assistance to their ill family member or friend. These caregivers were most likely caring for an ill spouse (31%) or child (29%).

The actual time spent performing tasks is often combined with time needed to travel to provide care. Approximately three-quarters (73%) of caregivers indicated that they did not live in the same household or building as their care receiver, meaning they often had to travel to reach the care recipients’ home. Just over half (52%), however, reported having to travel less than 30 minutes by car. Roughly 12% of caregivers provided help to a family member who lived at least one hour away by car.

While aging was the top reason for providing care, it rarely required 10 or more hours of commitment on the part of the caregiver. Only 13% of caregivers providing care for aging problems reported spending 10 or more hours a week on helping activities for their care receiver.

3 – 4.7 Time Frames

Caring for an ill or disabled family member or friend can span months or years. For most caregivers (89%), their caregiving activities had been going on at least one year or longer, with half reporting they had been caring for a loved one for four years or more. Longer-term caregivers (four years or more) differed from caregivers of less than one year. They were more likely caring for an aging friend or family member, while short-term caregivers were most commonly providing help to a cancer patient.

3 – 4.8 Regional Variations

The prevalence of family and friend caregivers varies somewhat across Canada. Four provinces had rates above the national average of 28%, including Ontario (29%), Nova Scotia (31%), Manitoba (33%) and Saskatchewan (34%). The higher levels of caregiving in Ontario, Nova Scotia and Manitoba were largely related to caring for a loved one suffering from a chronic health condition or disability, whereas in Saskatchewan, the higher level of caregiving was attributed to aging needs.

Quebec was the only province to have fewer caregivers than Canada overall, with 25% of Quebecers indicating that they had provided care to an ill, disabled or aging family member or friend in the past 12 months. The lower prevalence of caregiving in Quebec was true regardless of whether the primary health receiver was coping with aging needs or a chronic health condition or disability.

Levels of caregiving were similar among the census metropolitan areas (CMAs), though people living in the largest metropolitan areas were less likely to report providing care over the past 12 months. People in Toronto, Vancouver and Montreal reported levels of caregiving below the national average. This may not be unexpected, as these cities are often characterized by a high number of residents who live apart from their families, as may be the case with new immigrants and those who have moved away from their families to seek employment.

Individuals living in Thunder Bay, Oshawa, Regina and Winnipeg were more likely than those in other CMAs to provide care to a family member or friend, most often those suffering from a chronic health issue or disability, rather than problems related to aging.

Those living outside of CMAs were slightly more likely than those living in large urban centres to care for a chronically ill or disabled family member or friend. They were also more likely to spend 20 or more hours a week on caregiving.

Caregivers in non-CMAs were also more likely than those living in a CMA to travel one or more hours to provide care, and less likely to live in the same home or building. One explanation for the greater levels and intensity of care in rural areas, towns and smaller cities may relate to the available resources for the chronically ill, disabled or elderly, which may be fewer in remote communities.

3 – 4.9 Women More Likely Than Men to Provide Care

Historically, caregivers have been disproportionally women (Cranswick and Dosman 2008). This was also true in 2012, when an estimated 54% of caregivers were women. Although the median number of caregiving hours was similar between men and women (3 and 4 hours per week, respectively), women were more likely than their male counterparts to spend 20 or more hours per week on caregiving tasks. Meanwhile, men were more likely than women to spend less than one hour per week providing care.

The increased intensity of caregiving among women may be partly related to the type of tasks commonly performed by them. Women tend to provide care for activities that must be completed on a regular or set schedule. For instance, they were twice as likely as their male counterparts to provide personal care to the primary care receiver, including bathing and dressing.

Women were also substantially more likely to assist with medical treatments and housework, such as preparing meals. On the other hand, house maintenance or outdoor work, which can usually wait until the care provider has the time to do them, was more often performed by men.

3 – 4.10 Caregiver's Age

Reflecting the fact that the most common care recipients were parents, caregivers were most often between the ages of 45 to 54 years (24%) and 55 to 64 years (20%). The next most common group comprised young Canadians aged 15 to 24 years, accounting for 15% of all caregivers. This group was most likely providing care to grandparents (48%) and parents (25%).

Seniors aged 65 years and older were the least common group of caregivers, but they were most likely to spend the longest hours providing care. 23% of senior caregivers provided 20 or more hours of care per week, compared to 10% of those aged 15 to 24, 13% of those aged 45 to 54, and 17% of those aged 55 to 64. The longest hours of care among senior caregivers may be partly explained by seniors' higher likelihood of caring for a spouse, who typically requires greater time commitment on the part of the caregiver. Perhaps more so than other caregivers, seniors providing care may themselves have unique needs, given their advanced age. As a result, caregiving may have more pronounced impacts on their lives than on those of younger caregivers.

3 – 4.11 Sandwiched Between Caregiving and Childrearing

Caregivers have multiple responsibilities beyond caring for their chronically ill, disabled or aging family member or friend. In 2012, 28% of caregivers were "sandwiched" between caregiving and childrearing, having at least one child less than 18 years living at home. In most of these cases (82%), caregivers were raising children under the age of 15: 31% had children 4 and under, 38% had children aged 5 to 9, and 42% had children aged 10 to 14.

Balancing the demands of caregiving and raising children most often affected women, those between the ages of 35 and 44, and those helping their parent or parent's in-law. Despite the dual role, caregivers with children reported similar hours of caregiving as those without children, except for the longest hours of care. Caregivers with children were slightly less likely than other caregivers to spend 20 hours or more on caregiving activities.

Having less time with children was an often-cited outcome of providing care to a chronically ill, disabled, or aging family member or friend. About half of caregivers with children under 18 indicated that their caregiving responsibilities caused them to reduce the amount of time spent with their children. This feeling was magnified among those spending the greatest number of hours per week on their caregiving responsibilities.

Time spent on caregiving also meant less time spent with spouses. Of the 65% of caregivers who were married or in a common-law union, about half reported spending less time with their spouse as a result of their caregiving responsibilities. A loss in family time often accompanied a reduction in time spent with friends, on social activities, and relaxing or taking care of oneself.

3 – 4.12 Trends in Caregiving

The aging of the population, higher life expectancies and the shift in emphasis from institutionalized care to home care may suggest that more chronically ill, disabled and frail people are relying on help from family and friends than in the past.

Between 2007 and 2012, the number of caregivers aged 45 and over increased by 760,000 to 4.5 million caregivers, representing a 20% increase in the number of caregivers over the five years.

The amount of time caregivers aged 45 and over devoted to their caregiving responsibilities did not change from 2007 to 2012. In both years, caregivers spent a median of 3 hours per week providing care for their family member or friend.

3 – 4.13 Caregiver Challenges

Overall, most caregivers (95%) indicated that they were effectively coping with their caregiving responsibilities, with only 5% reporting that they were not coping well. However, the feeling of being unable to cope grew with a greater number of hours of care. By the time caregivers were spending 20 or more hours per week on caregiving tasks, one in ten (10%) were not coping well.

In addition, while most were able to effectively manage their caregiving responsibilities, 28% found providing care somewhat or very stressful and 19% of caregivers indicated that their physical and emotional health suffered in the last 12 months as a result of their caregiving responsibilities. In both cases, these consequences were magnified with the intensity of care— the number of hours per week.

The health consequences of caregiving were even more pronounced when caregivers were asked specific questions on their health symptoms.

Over half of caregivers felt worried or anxious as a result of their caregiving responsibilities, while about half felt tired during the past 12 months. Other common symptoms associated with providing care included feeling short-tempered or irritable, feeling overwhelmed and having disturbed sleep.

In the end, roughly nine in ten caregivers felt that the experience of providing care was rewarding, with more than one-third indicating that the caregiving experience had been very rewarding. Furthermore, 70% expressed that their relationship with the care receiver had strengthened over the course of last 12 months.

3 – 4.14 The Impact on Work

In addition to family obligations and personal commitments, 60% of caregivers were also juggling the demands of paid work. This was true for 81% of caregivers with children and 51% without children.

At times, providing care resulted in disruptions to normal work routines. About four in ten employed caregivers indicated that they arrived to work late, had to leave early, or take time off during the day to care for their ill family member or friend. This figure increased to 54% for those providing 20 or more hours of caregiving per week.

Other consequences on employment were more long-term, possibly impacting the caregiver's career and/or benefits. An estimated 15% of employed caregivers reported cutting down on their regular weekly hours of work to accommodate the caregiving needs of family and friends. This became a greater reality with increased intensity of caregiving activities. For instance, about one-quarter of caregivers providing help for more than 15 hours had to reduce their regular paid work hours.

A reduction in paid work hours can have consequences on both employee benefits and household income. Among employed caregivers who reduced their hours of work, 14% reported losing some or all their benefits, such as extended health benefits, dental benefits, employer-provided pension, life insurance, and prescription drug plans. While reduced hours can also impact pay, the largest proportion of caregivers (31%) reported a household income of $100,000 or more, followed by an income of $60,000 to $99,999 (22%). In fact, caregivers were more likely than non-caregivers to report an income of $60,000 or more.

Closely related to income is career advancement. In 2012, 10% of employed caregivers turned down or did not even pursue a new job or promotion because of their caregiving responsibilities. Again, the more intense the caregiving responsibilities, the higher the likelihood of the caregiver postponing or forgoing career opportunities. Four in ten caregivers sought a less demanding job because of their caregiving duties.

The General Social Survey also asked employed caregivers on their satisfaction with their work-life balance.

While most caregivers were satisfied with the current balance between their work and home life, they were less satisfied compared to those not providing help. Furthermore, feelings of dissatisfaction with work-life balance, while relatively rare, were more often identified by caregivers than non-caregivers.

It could be expected that employed caregivers spending more hours on caregiving responsibilities would have less time for other activities and would, in turn, be less likely to have a good work-life balance. However, few significant differences in work-life balance emerged based on the intensity of care. Only those spending 20 hours or more a week on caregiving duties were significantly less likely than those spending 2 to 4 hours to report having a good balance between home life and work.

Satisfaction with work-life balance did not vary based on the caregiver's relationship to the care recipient. That is, there were no significant differences in work-life balance between those caring for a child, spouse, parent, other family member or friend.

3 – 4.15 Financial Help

The financial impacts related to caring for a loved one can be significant. Lost days at work may reduce household income, while out-of-pocket expenses, such as purchasing specialized aids or devices, transportation costs, and hiring professional help to assist with care, can be borne from caring for a loved one. In many cases, financial support, from either informal or formal sources, can ease the financial burden associated with caregiving responsibilities.

Overall, about one in five caregivers (19%) were receiving some form of financial support. The most common was help from family and friends, with 12% of caregivers indicating that they had received this type of financial assistance. In 2012, 7% of caregivers received help from a government program and 5% received federal tax credits, such as the caregiver tax credit, infirm dependant tax credit and medical expense tax credit.

Two related factors increased the likelihood of financial support: the intensity of caregiving and the relationship of the caregiver to the recipient. Caregivers spending the greatest number of hours on caregiving tasks were more likely to receive financial support, from either informal or formal sources.

3 – 4.16 Summary

In 2012, more than one in four Canadians reported providing care to a family member or friend with a chronic illness, disability or aging needs. These caregivers were most often caring for a parent. Age–related needs and cancer were the most common reasons for providing care.

Among the top activities performed by caregivers were providing transportation, doing housework and maintaining the house or outdoor work.

Even though caregivers are juggling multiple responsibilities, most indicated that they were effectively coping with their caregiving responsibilities. That said, feelings of worry, anxiety or tiredness affected at least half of caregivers.

Caregivers have multiple responsibilities. Close to half of the caregivers were between the ages of 45 and 54, the age at which many Canadians still have children living at home. About 3 in 4 caregivers were married or living common-law. Others also juggled employment with family and eldercare tasks, as more than half of the caregivers were employed.

The profile of caregivers is different than that of non-caregivers. Caregivers tended to be younger, and were more likely to be women, employed and married than non-caregivers.

3 - 5 THE FIVE STAGES OF CAREGIVING

Caregiving is like being in a dramatic movie where the inevitable end is already known but the story itself is unpredictable and full of twists and turns, highs and lows, peaks of joy and sorrow, high anxiety and quiet satisfaction. Although you already know the ending, looking after an elder is full of surprises.

But there is, however, a distinct patter and storyline to it all, despite the day-today rewards and hurdles. Family caregiving typically unfolds into five distinct stages. Knowing those stages, including their challenges, costs and opportunities, can give caregivers a head start.

3 – 5.1 Stage One: Independence

This may not seem like a "caregiving" stage at all, but stage one is the period when the elderly do not want any help. It is often a time when adult children "see" their parents as older and less capable than do the parents themselves. Regardless of perceptions, seniors at this stage are usually quite capable of taking care of themselves, though perhaps not in the ways preferred by their children. They may indeed be experiencing some of the chronic ailments associated with aging (e.g., heart conditions, diabetes, arthritis, hearing or visual impairments), but they are able to compensate on their own for any loss of function. Some adult children take pleasure in seeing their parents at this stage. But many others worry about their parents' health, judgment and what will happen if a parent falls seriously ill. Besides worrying, there are indeed some proactive things that adult children can do at this stage.

This is a good time to discuss legal and financial planning. Make sure the elder is aware of such things as wills, living wills, powers of attorney, financial plans, and insurance options. Encourage them to start to plan if they have not already done so.

There is a vast array of educational material in books, magazines, newspapers, and online on the topic of aging. The material in this program is designed to educate you about the emotional, physical, social and spiritual dimensions of aging, so that you can be better aware of the experiences and challenges experienced by elders.

3 – 5.2 Stage Two: Mild Care

At this stage, the elder is starting to experience a need for assistance. The children may have a rotating schedule for caring for/checking in on her every day. The elder may be suffering from any number of conditions (severe arthritis, a heart condition, losing sight and hearing, showing some early signs of dementia). Assistance for many aspects of daily living, including meal preparation, house cleaning, laundry, transportation to doctor's appointments and grocery shopping is required.

This situation is extremely stressful for everyone involved. It is becoming apparent that the elder needs assistance 24/7 or be in a facility with continuous care and monitoring.

The elder, however, is refusing, does not want to even consider outside help and does not want to leave her home and all the memories of the past 60 years. The elder will likely firmly resist any attempts to hire outside help, either citing the cost, denying the need or both. What most seniors will accept at this stage is family help: assistance with meals, transportation, shopping or other assistance.

At Stage Two, seniors are more likely to accept technical devices that help them and their loved ones to stay in touch. For example, emergency call systems are increasingly popular – like a pendant or a wristband that they can activate if they fall or need help.

Internet-based video systems have become more sophisticated and less expensive and enable elderly parents and adult children living far away to stay in touch visually as well as by voice. More exotic electronic systems are also coming onto the market now, including "smart homes" with a variety of monitoring devices to keep track of the occupant's activities and "carebots"—sophisticated mobile robots that can also serve as helpful communication and monitoring devices.

Finally, Stage Two is a time when a retirement residence is appealing to some seniors, depending on their preferred lifestyle and their financial means. Retirement residences are multi-unit residential buildings with amenities to make life easier for the seniors living there. These residences are not healthcare facilities. Instead they stress independent living and thus are often acceptable to independence-minded elders.

3 – 5.3 Stage Three: Supportive Living

At this stage, the elder is dealing with many issues. He or she likely has problems with walking and with other daily living activities. One spouse who has been assisting another may be starting to need care themselves. The elder likely needs the help of Personal Support Workers to assist with meals, bathing and dressing, the elder is likely also relying on family and friends for transportation to medical appointments and grocery shopping.

In Stage Three, elders are trying to cope with multiple disabilities and often chronic pain. This is the stage at which seniors begin to accept outside caregivers who can help with personal care and/or healthcare. Family members are also often heavily involved in helping to find, hire and coordinate formal caregivers (personal support workers, nurses, therapists) and themselves assisting their elderly loved one with activities of daily living.

Family caregivers can benefit at this stage from a variety of services and programs, including community intake and referral services; homecare and home healthcare agencies; public healthcare facilities offering geriatric and/or psychogeriatric assessments of an elder; and educational programs, books and online services that can help caregivers learn about and find resources and navigate the system. Although most elders at this stage have a very strong desire to remain in their own home (no matter what difficulties this presents), some will accept the alternative of assisting living residences (sometimes called "retirement homes"). Assisted living facilities, both private and publicly funded, typically offer private or semi-private bedroom accommodations, a dining room, a full activity and recreational program and trained staff who provide direct assistance to residents needing help with any of the basic activities of daily living (eating, dressing, bathing, grooming and mobility).

3 – 5.4 Stage Four: Complex Care/Crisis Management

At this stage, the elder may have difficulty speaking, have poor balance when walking, is unable to dress or feed himself and no longer recognizes his family. A personal care worker may have been hired to help dress and feed the elder. Lack of sleep and exhaustion may be affecting the family caregiver whose own health may be deteriorating.

Stage Four is a difficult and often painful stage for all concerned. The elder's physical and/or mental condition has declined to such a degree that he or she is dependent on others for most of the care. There are usually multiple health conditions challenging the elder, requiring a variety of treatments and therapies. If cognitive problems (thinking, memory, impulse control, judgment) are a part of the problem, close, skilled supervision is also required—often around the clock.

Despite the involvement of formal caregivers, the levels of care in the home available to the family at this stage may be inadequate or too expensive, leading to one crisis after another.

At this stage, it is common for the only thing preventing a nursing home admission to be an earlier promise to the elderly parent or to one's self to never place the parent in such an institution.

Self-care for family caregivers is not a luxury at this stage—it is a necessity. This is the stage of family caregiving when the caregiver, be it an adult child, spouse, sibling or friend, finally "burns out" and gives up, resulting in a major crisis. Self-care for caregivers, including stress-management programs, meditation and yoga, is invaluable. So are therapy programs to help the caregiver deal with depression and sleep deprivation.

Community referral services can help the caregiver locate these programs as well as respite care programs. A competent geriatric care manager can also help. Geriatric care managers are social workers or nurses specifically trained to assess seniors' needs, devise a comprehensive plan of care and help a family coordinate and manage the care and caregivers required.

3 – 5.5 Stage Five: Dependence

At some point, many families come to see that the well-being of both their elderly loved one and of the remaining family will be better served by a nursing home admission. In fact, at this stage the patient is often safer and more comfortable with 24-hour institutional health and personal care than with a patchwork of homecare services.

Anyone who has visited a nursing home, even the best ones, knows how difficult it can be to see a loved one there. However, even here there are valuable resources to assist family members. Written materials can coach family members on how best to advocate for the treatment and welfare of a loved one in a nursing home. There is also usually a social worker in the facility with whom to discuss concerns and feelings, especially feelings of grief and loss related to the current state of a loved one. Finally, many nursing homes organize family councils where family members can address issues of common concern.

Not all aging individuals and their families pass through all these five stages. Nor do they pass through all stages at the same pace. We know that most Canadians die either at home or in a hospital and never even see the inside of a nursing home. But the five family caregiving stages provide a framework for understanding the main needs and issues for elders and their families.

3 - 6 CAREGIVER CLASSIFICATIONS

Traditionally the types of caregiver have been divided into formal and informal such that formal refers to health care professionals and informal refers to family and friend caregivers. However, at the request of caregivers the distinction between formal and informal is being dropped. Caregivers, nationwide, have expressed concern that the term "informal" diminishes the importance of their roles as caregivers today. Caregivers are assuming more responsibilities and providing more complicated care due to de-institutionalization, early discharge, day surgery, cutbacks in public health services and an aging population.

The mix of family and professional sources of care differs across age groups. Most elders aged 65–74 received all their care from family and friend sources. However, by age 75, especially for women, family and friend care was supplemented or replaced by care from professional sources.

3 - 6.1 Formal Caregivers (Now Called Care Providers)

Doctors, nurses, physician's assistants, medical aides and assistants, dieticians, physical therapists, respiratory therapists, social workers, psychiatrists, and chaplains (and sometimes interns or residents in teaching hospitals) can all be part of the medical team that provides formal Caregiving. Your loved one may require care at home, in hospitals, in emergency rooms, in clinics, or in hospices.

In working with formal caregivers, it is desirable to avoid relationships with them that are either extremely dependent or adversarial. In dependent relationships, people living with illness and their caregivers believe that formal caregivers have all the answers. They do not question or search for alternative solutions about the illness or its treatment. At the other extreme are adversarial relationships, those in which people with illness and their caregivers trust nothing that the medical team does, and challenges everything they do.

The ideal for working with a medical team is to become an active part of it, advocating for the person who is living with illness, remembering and clarifying details, such as diagnosis, prognosis, medication types and schedules, and treatment options that may escape a patient.

When one is ill clarity of thought and remembering details may be hindered by upset or pain.

3 - 6.2 Informal Caregivers (Now Called Family Caregivers)

Family and friends are critical to the well-being of people with illness, and Caregiving can be both rewarding and exhausting. Many people receive multiple diagnoses, or even incorrect diagnoses, leaving everyone feeling as if they are on a psychological roller coaster.

Some caregivers live with the person who is ill, while others may be neighbours, or at a distance.

Family caregivers will be dealing with the reactions of people living with the disease or illness, and those reactions may include denial, anger, depression, confusion, and several other emotions. At the same time, family caregivers will be dealing with their own reaction to the diagnosis. Much of what caregivers do will be to help with the logistics of medical care and treatment. According to a recent survey, 39% of women and 46% of men reported receiving all their care from informal sources. This was about the same number as in 1996.

3 - 6.3 Other Caregiver Classifications

It is possible to slice and dice up caregivers in a variety of other ways. A few of these different classifications are covered below.

3 - 6.4 Primary Caregivers

The person (usually the spouse or adult child) that takes on the main or the day-to-day responsibility of caring for the physical, psychological, and/or social needs of another person is the primary caregiver. This type of caregiver will make important decisions that will affect the recipient. The primary caregiver handles any matters that the individual cannot.

3 - 6.5 Secondary Caregivers

This type of caregiver acts as a backup - performing many of the same functions as the primary caregiver.

3 - 6.6 Occasional Caregivers

Caregivers in this category will provide one or more services on an irregular basis. Some of these services could be simple things like transportation issues, helping the elder with banking, or assisting with household chores.

3 - 6.7 Long Distance Caregivers

A growing number of family members are caring for older relatives who live long distances away. Canadian society is a highly mobile one and family caregivers may not see their relatives more than a few times a year. It is essential that time spent together is used to ensure independence, health, and safety.

Long distance caregivers must discuss and plan for financial, legal, medical, social, and emergency issues. They must also engage relatives to evaluate the current situation, recognize problems, activate informal supports (friends, church, and neighbours), and coordinate community services.

Caregiving can be a stressful experience, especially from a distance. Even when caregivers are not physically providing support for a loved one, they are still mentally coping with the personal difficulties associated with the illness.

Support through groups, individual counseling, or personal friendships and family all give the caregiver comfort to learn that they are not alone.

Long distance Caregiving tips:

- During visits, observe hygiene, eating habits, and condition and safety of the home
- Review financial records, if possible
- The caregiver should allow enough time to get things done during visits
- Identify community resources. Establish local support systems and back-up plans, including neighbours or friends
- The caregiver should recognize that how they see the situation may be very different from how the care recipient sees it

Among the many issues that exist for long distance caregivers:

- Travel may be a financial and geographically challenging factor
- Guilt may develop from not being physically present and lacking familiarity with services available for a loved one
- The task of arranging assistance may become so overwhelming as to exacerbate and impede the Caregiving process

3 - 6.8 Employed Caregivers

As we know, many caregivers are employed themselves. It is important that employed caregivers set realistic expectations.

It may also be valuable to do all the following:

- Talk with your spouse, your children, your employer, and parents about how you feel about your Caregiving responsibilities. Ask for suggestions
- Explain to your employer or supervisor, if possible, that you may need flexible work scheduling at certain times
- Get information about the medical condition of the elder from his or her physician and other knowledgeable service providers

- Ask for help. Seek out and use community services, both for yourself and the person for whom you are caring
- Plan some "time-outs" for you and your spouse
- Make time for yourself. You will not be good in any of your roles, as spouse, parent, or employed caregiver, unless you stay physically and mentally healthy

3 - 6.9 Tips for Male Caregivers

While most caregivers are women, a growing number are men. Male caregivers are often surprised at their ability to take on an unfamiliar role. They help by finding, managing, or providing appropriate assistance with housekeeping, finances, meals, bathing and dressing, shopping, and transportation.

Caregiving responsibilities may create overwhelming physical, financial, and emotional strain on the caregiver, however. While there are few services targeted solely to male caregivers, men are usually welcome in existing support groups.

Men may also be more likely to use technology to establish a phone-based caregiver network or to access a computer bulletin board to receive information and support.

Male caregivers should keep the following two things in mind:

- Ask for Help
- Be Specific

Sources of help include family, friends, church members, social clubs, councils on aging, home health agencies, and social service departments.

Decide what type of help is required. Develop a schedule of who will help (family, friends or agency service staff), and how often they will help (daily, weekly, or monthly).

As the baby boomers come of age and as their numbers make further demands on community services, men will find themselves Caregiving in the Caregiving role. Unless your community identifies specific supports for male caregivers, the best strategy is to tap into existing services.

3 - 7 THE SANDWICH GENERATION

The "Sandwich Generation" is composed of a substantial number of middle-aged parents who have children still at home, but who also have elderly parents who need their help. Nearly half of all boomers age 45 to 55 have children at home and parents who are still living.

In the 1990s, people lived longer, they postponed marriage, more children were living at home and going to college, and an increasing number of adult children were returning home after divorce or loss of employment. Consequently, larger numbers of mid-life couples felt caught in the middle between the demands of their aging parents and those of their own children. These were couples and individuals between the ages of 45 and 65 who assumed their children would grow up, leave home, and live as independent, self-supporting adults. People in the middle years also expected their aging parents would remain independent, self-supporting, and healthy well into their late adult years. When their parents' health began to fail, those in their middle years thought appropriate care centres would exist where their parents could receive necessary services and where children and grandchildren could visit. They also assumed that retirement benefits, coupled with government benefits, would cover most of the expenses. At the same time, these middle-aged adults believed they could travel and do some special things in life that had been postponed while their children were growing up.

Things have not worked out as they had expected. In addition to demands at work for those in mid-life and at the peak of their careers, there were additional demands introduced by teen and adult children, and others by their frail parents, who increasingly make demands of their time.

The Sandwich Generation are under enormous stress - torn between aging parents needing care and providing care for their own children. Many baby boomers are essentially doing double duty as caretakers for both children and parents - wedged between the responsibilities of raising their own children and helping ailing parents, often while working full time. This balancing act is extraordinarily difficult. To make matters worse, some middle age adults are not just members of the Sandwich Generation - they are part of the "double decker" Sandwich Generation - caring for their children, parents, grandparents and even great grandparents.

In short, the stereotypical "*me*" generation is now becoming an "*us*" generation.

Experts believe that many middle age adults will spend more time looking after their parents than their own children.

3 - 7.1 The Needs of Three Generations

Most members of the Sandwich Generation share the same concerns:

- The need for information and referrals to child care providers and elder care services
- A need for alternative work options that allow them to work outside the traditional 9-to-5, Monday-through-Friday week
- Strained relationship with elderly parents caused by care taking responsibilities
- Concerns about leaving young children with caregivers, and a need to learn better parenting and communication skills

Teens and adult children want independence despite their temporary state of dependence. They value their parents' guidance and need their opinions as a sounding board as they start their own adult lives. They want to be accepted and respected, even if their ideas and lifestyles are different. They need some security and support, both verbal and often monetary, as they enter their adult years. Most of all, they need their parents' patience and unconditional love.

People caught in the sandwich generation need help! They need to have some of the pressure taken off—they need solitude, space, and appreciation from both generations. They need time with their peers, time to pursue the peak of their careers, and time to have *their turn* to do the things they want to do. At the same time, the Sandwich Generations' parents want to be independent, even under increasingly difficult circumstances. They need interaction with their grandchildren and their peers.

Facing a future of increasing losses and declining health, they need to be accepted, to have their children's involvement and emotional support, and to be included in family life.

The overriding need of each generation is to have a sense of control and a sense of purpose about their life. Individuals who feel in control of life generally experience greater life satisfaction.

A perception of control influences how people proceed in life, approach a crisis, and make decisions. If there is an internal sense of control, there is a greater feeling of power over one's environment and decisions.

If control seems external, there is a feeling of little or no control over what happens, and there may be an unwillingness to make decisions. People who are externally controlled tend to experience more psychological distress and illness. Many people in this group feel that they have little choice. A lack of communication, infrequent demonstration of affection, and failure to work out differences can result in misunderstanding, frustration, resentment, and alienation.

The following are some helpful suggestions for members of the Sandwich Generation as they attempt to deal with the challenges they face:

- Take care of yourself (If you do not take care of yourself, then how can you take care of others?)
- Set aside time for spiritual reflection and renewal
- Take time for your own marriage and personal life
- Do not neglect your own family to take care of parent(s)
- Keep the lines of communication open. Talk about things. Where there is communication, there is healing
- Do not take anything for granted

The chart below lists some of the needs of each generation. The Sandwich Generation is caught in the middle between: (1) what their children want and need, (2) what they want and need, and (3) what their parents want and need.

Table 3 - 2 Needs of the Sandwich Generation

Caught in the middle between THEIR CHILDREN & THEIR PARENTS		
What our kids want and need	**What we want and need**	**What our parents want and need**
Independence	Help	Acceptance
Respect	Appreciation	Independence
Sounding board	Pressure off	Respect
Separate entity	"My turn"	Control
Patience	Independence	Sharing
Guideline	Listening ear	Involvement
Flexibility	Acceptance	Emotional support
Acceptance	Time with my own generation	Interpersonal relationships
Security	Solitude	Interaction
Money	Space	Inclusion
Support	Unconditional love	
Make choices		
Unconditional love		
Control of own life		

3 - 7.2 Work Challenges

Imagine, you are on the move with your career! You have finally got the job of your dreams! You are finally opening that small business you have always dreamed of!

Then, out of the blue, you are faced with the needs of an aging family member.

In order to remain productive members of the workforce, members of the *Sandwich Generation* and other working parents need practical help balancing their work and family obligations.

Organizations that recognize this need now offer services to help employees, including referrals to child and elder care providers, crisis management services, workshops, family-friendly policies, and information on other community resources.

Some organizations also offer support groups and alternative work options, such as part-time job-sharing, a compressed workweek, and flex time, all of which allow employees to adjust their work schedules to accommodate family and their care-giving responsibilities.

These services are often provided through an organization's Employee Assistance Program (EAP) or the human resources department. Employees facing difficulties related to Caregiving should discuss their problems with their EAP personnel and determine what resources are available.

Fortunately, more organizations have been proactive in offering Caregiving assistance.

Information and referral programs were the most common initiative, adopted by 37 percent of Canadian companies. Few organizations offered financial assistance for caregivers, respite care, or emergency-care programs.

Complicating matters, most employees are reluctant to talk about Caregiving responsibilities in the workplace. This is due to a stigma about elder care, as it does not operate on the employer's "time clock."

But as caregiver needs increase, baby-boomer employees will demand more of their employers than just a phone number to call for resources in the community. Overall expectations will increase. Employees will want case coordination, case management, intensive consultation and assistance.

3 - 7.3 Work Life Balance

A caregiver's work is much like having another job, with the many responsibilities that would go along with it.

If you are trying to juggle your career and caregiver duties, you should seek the help of health care agencies, homemaker services, family, friends, and neighbours. You will find that these avenues could be a lifesaver for you. Do not get caught up in the thinking that because you are asking for help, you are a failure at Caregiving. In fact, the opposite is true. Asking for help shows that you are a dedicated caregiver.

The following information provides some suggestions on how to manage the conflicting demands of work and caregiving.

3 - 7.4 Career Evaluation

You may find that your role as a caregiver is conflicting too much with your chosen career. If this happens, you may have to make some important decisions about your future direction in Caregiving, or your career.

What, for example, will you do if your current career requires a great deal of traveling? You may have to consider another career, or perhaps a position change within the same field.

3 - 7.5 Flextime

Having to alter one's work patterns may mean working split shifts or leaving early and then making up the time on weekends. A change of work pattern was required by more than 25% of female caregivers aged 45–54, while men in the same age group reported a change in work pattern about 12% of the time. Reducing hours of work was common for all caregivers aged 45–54.

Many companies currently allow some form of flextime hours. This term is used when the employee can choose to work certain hours, or a specific schedule that is different from normal work hours. Flextime can be a great feature for caregivers since they do not know when they will be needed by their loved one or for how long.

Flextime is a good example of a win-win situation. The employee gains needed flexibility - while from the company's perspective, the job still gets done.

3 - 7.6 Establish A Home Office

With current technology (Internet, cell phones, and fax machines, etc.) the possibility of doing work from home can become a reality.

This is a great flexible tool, as it allows the caregiver to get the job done and still be available to look after the care recipient. If not currently available, you may want to propose the idea of telecommuting to your employer.

A home office can reduce the tension that you will experience between your career and caregiver duties - and allow you to care for an elder at your own pace.

3 - 8 THE CAREGIVER REALITY

Many of today's caregivers are different from those of the past.

As more women have entered the work force, more caregivers have had to juggle responsibilities to family members and to employers.

Historically there have tended to be many multi-generational families who lived together and helped with their elders. But society has changed. Many families have two career couples or may live far distances from family members.

As a result, most families must make tough choices, as loved ones grow older.

3 - 8.1 The Needs of the Caregiver

Make no mistake about it; Caregiving can be time consuming, demanding, and exhausting. In your role as caregiver, you are caring for someone else's needs; you are responsible for helping a person, who was once independent, and could perform simpler and more difficult tasks and functions of daily living.

People will always ask about the person for whom you are caring yet will rarely ask about how you are feeling. When this starts, you may begin to feel isolated, angry, guilty, and confused.

The caregiver is usually the last to receive care. Despite this, caregivers must make themselves a priority. If they are not healthy themselves, then how can they care for someone else?

Caregivers need to ask themselves the following questions:

- What do I need to be happy and healthy?
- What kind of support do I need?
- What sort of situation do I want?
- What do I want for the care recipient? For my own family? For myself?
- What are my basic rights as a caregiver?
- What do my spouse, children, and work requirements demand?

3 - 8.2 The Caregiver's Creed

Questions a caregiver should ask themselves to determine whether they are effective:

- Am I taking care of myself?
- Am I assuring there is balance in my life?
- Am I trying to establish a workable schedule?
- Am I learning where and how to ask for help?
- Am I investigating support groups for my family and myself?
- Am I working on developing patience?
- Am I learning about the disease and its long-term ramifications?
- Am I learning from others about how to be a balanced caregiver?

- Am I able to retain my sense of humour?
- Am I aware of my limits?
- Am I trying to learn how to live elegantly under these trying circumstances?

3 - 9 CAREGIVING DIFFICULTIES

Caregivers often find themselves caught between the aging elder's needs and the needs of their spouse, children, and career. You, your spouse, and your family can feel the everlasting effects of this personal dilemma. Providing care for the elder can quickly consume family time. This situation requires a solid work ethic on your part.

You may be so wrapped up in your career and your second job of Caregiving that you may not even realize that your spouse and family are feeling left out. They may not mention anything to you and suppress any emotions to either protect you or because they feel guilty about them.

Communication and understanding is the key to making Caregiving work. You may even consider allowing your family's help in the Caregiving process.

There is nothing wrong with feeling that your spouse and children come first. It is a natural emotion and understandable. You must care for your family first at times before your attention is given to the care recipient. By doing this, you will become a better caregiver.

3 - 9.1 Caregiving and Guilt

Many caregivers feel that they are struggling to balance love, Caregiving, and guilt. Many experts say that Caregiving is so demanding that in most cases, the caregiver feels inadequate when it comes to providing the level of care that they would like to.

Emotions such as guilt can take their toll on the health of the caregiver. Guilt can be the most devastating of all the emotions that the caregiver experiences. It usually hinges around not being able to do enough for the care recipient.

Guilt can become a real issue when the caregiver:

- Starts to experience expectations that are unreal
- Finds it difficult to ask for help from friends and professionals
- Feels that somehow there is something they could, might, should, and would have done
- Feels powerless over the situation

3 - 9.2 Managing Guilt

You cannot repay your parents, no matter how hard you try. Many caregivers think that they owe their parents care because the parents cared for them through their childhood.

They gave us life and that is something beyond reach in any attempt to reciprocate. If we were adopted, we were given a gift that we can never repay. If we come to understand this, and to know the truth of this, perhaps we will stop trying to do everything and stop allowing ourselves to be pulled so strenuously. When we learn to eliminate the guilt, we can become better caregivers.

If caregivers are providing care out of guilt, then they will never be ahead of the game. In many cultures, most parents do not expect their sons and daughters to look after them. The right attitude to take is that of someone who wants to provide a level care for their parents, or other family member unconditionally, and not as someone who feels that they owe a debt.

3 - 9.3 Guilt as a Sickness

Guilt can eat away at an individual without them knowing it. Time restraints may set in and the person feels guilty because they cannot spend more time. Guilt may set in when the time comes to put a relative into a nursing home.

Aging relatives have also been known to make the caregiver feel guilty, due to the quality or amount of time that the individual is providing. No matter how the situation is perceived, guilt is not healthy.

Caregivers should not feel guilty about putting themselves and their families first. Having control over guilt is paramount; otherwise matters may be taken out on the care recipient mentally or physically.

3 - 9.4 Moving Past Guilt

Forgiveness and acceptance are two virtues that are required of the caregiver and the person who is being cared for. A caregiver’s job is to provide the best care possible, either by themselves or with the help of the many available avenues and alternatives.

Once guilt is behind the caregiver, they will become more confident in what they are doing, but above all, they will be happy.

3 - 9.5 Preventing Guilt

- Get help from community and professional resources
- Ask family and friends for help
- Get access to information, especially during a crisis
- Consider joining one of the many support groups that are available
- Know your limits
- Do not be hard on yourself for your mistakes
- Learn to delegate any Caregiving chores
- Always remember that your best is good enough

3 - 10 CAREGIVER STRESS AND BURNOUT

No matter how loving and rewarding the relationship, Caregiving usually involves some personal sacrifice and results in stress for the caregiver. Caregiving to the chronically ill in the beginning averages 25–30 hours per week for four or five years and often leads to total care. When the elder becomes more dependent due to health problems or frailty, Caregiving usually becomes more difficult and begins to take a toll on the caregiver.

Caring for a relative who is aging can at times be a very difficult job. In fact, it can reach a point where it is considered stressful. Sometimes when we are put into these situations, our love for that person is much like not seeing the forest for the trees.

We think that we can handle any stress that would result from caring for them. The reality is that in most cases, unless handled correctly, the caregiver will be overworked, overwhelmed, and excessively stressed.

A caregiver’s job can demand taking care of someone 24 hours a day, seven days a week. It can be demanding, stressful, and difficult. The position of caregiver provides for a high rate of burnout. How do you know that you are suffering from burnout?

If you feel that you are experiencing one of the following warning signs, you may be heading for burnout.

3 - 10.1 Emotional Burden

Emotional burden is one of the most difficult problems caregivers experience. For spouses, emotional burden results from concern over their partner's health and safety.

While providing care, spouses also must redefine long-held patterns of responsibilities, such as household financial management, meal preparation, and letter writing and calls to friends and relatives.

In our society, married individuals tend to see themselves as part of a couple and rely heavily on their spouse for reassurance and assistance when in need. The illness or disability of a spouse can undermine the caregiver's sense of identity and source of support. Spouses who are caregivers also sometimes experience guilt from feelings of anger or resentment at a partner whose disability has interrupted plans for retirement. Guilt may also arise when the healthy spouse begins to dislike a partner whose personality has changed because of illness.

Caregiving imposes time demands and restrictions on personal freedom. These restraints are associated with emotional strain. Caregiving disrupts domestic routines, decreases discretionary time for personal interests and leisure and social activities, prohibits vacations, and requires that work schedules be rearranged.

3 - 10.2 Physical Burden

Caring for a frail elder requires strenuous physical labour, which can affect the caregiver's health. Often the caregiver's sleep is disturbed. She or he must be constantly attentive and alert, and this is tiring. Spouses of the frail elderly, who tend to also be old, experience more health problems than other caregivers or their peers, who are not caregivers. Declines in a caregivers' health are a major cause of institutionalization of the elderly.

3 - 10.3 Financial Burden

Although the emotional pressures of Caregiving are great, financial strains are also problematic, in both the short and long-term. Worries about inadequate insurance coverage and about paying for nursing home care add to the strain of Caregiving.

Caregivers frequently must leave the labour force to care for elderly relatives, which results in lost wages, lost opportunity to earn a higher income, and lost opportunity to secure greater retirement benefits.

Husbands generally have assumed responsibility for providing financially for the family and are likely to be distressed over the future impact of their illness on their wives.

Women do tend to live longer and to marry older men, and as a result, they are more likely to shoulder the financial impact of their spouse's terminal illness.

When these emotional, physical, and financial burdens of Caregiving increase, many caregivers have mixed emotions about their Caregiving role. They love their family member and are glad to provide care, but also feel resentful about the loss of privacy, of control over their time and financial resources, and of the future for which they had planned and hoped. They may feel that Caregiving interferes with time for themselves and their families, or with the advancement of their careers.

3 - 10.4 A Special Note for Women

Women appear to be particularly susceptible to the stress and burden of Caregiving. Many women feel that somehow, they are not doing enough for their parent, and constantly try to do more.

Women who are employed outside the home find that as the elderly person's health deteriorates, it is increasingly difficult to work and to continue providing care. Employed caregivers report that they miss work, lose pay, have reduced energy for their jobs, and have limited job choices because of their Caregiving responsibilities. 12% of caregivers eventually quit their jobs due to work and Caregiving demands, and 55% reduce their work hours. Professional women are less likely to quit and are more inclined to hire help. Many employed women believe that it is better to pay someone to care for an elderly parent than to leave their employment.

3 - 10.5 Determining Stress Level

Caregivers can ask themselves the following questions to determine their stress level:

- Are you suffering loss of appetite or other eating disorders?
- Are you eating more?
- Are you eating less?
- Are you gaining or losing weight?
- Are you eating too much junk food?
- Are you skipping any meals?
- Do you begin to cry unexpectedly?
- Do you laugh at times that are not funny?
- Are you over sensitive to the comments of others?
- Do you ever wake up and not know how you are going to get through the day?
- Do you feel like tasks are accumulating and you will never catch up?
- Are you starting to withdraw into yourself and shutting the world out?
- Are you harbouring emotions within yourself?
- Are you beginning to avoid or confront other people?
- Have you ceased participating in activities that you used to enjoy?
- Are you avoiding phone calls or other social advances of others?
- Are you making excuses for not seeing people?
- Has your job concentration decreased? Are you spending time worrying about non-job-related activities?
- Are you taking excessive time off work to attend to the care recipient?

- Has your superior mentioned that you do not seem as focused as you once were?
- Have you stopped buying clothes for yourself?
- Is your personal hygiene suffering? Have you lost interest in looking your best?

If you are beginning to experience any of the above signs, it may be time for you to seek professional help. Remember, in order to do the best that you can do, you must take care of yourself. Otherwise, you are not going to be of help to anyone— especially the number one person in your life… you!

3 - 10.6 Stress Warning Signs at a Glance

- Loss of energy
- Feeling out of control
- Exhibiting uncharacteristic emotions and actions
- Loss of interest in the people and activities you once found pleasurable
- Isolation
- Overuse of alcohol, sleeping pills, caffeine, or nicotine
- Increased health problems
- Difficulty sleeping - one-quarter of caregivers say their sleep patterns have changed due to Caregiving
- Change in appetite
- Loss of memory
- Lack of concentration
- Irritability or impatience
- Suicidal thoughts
- Anxiety or panic attacks

How does the caregiver manage stress? Stress can be considered a natural response to difficult situations. It can be managed by a combination of changing the circumstances and changing your response to the circumstances.

The important thing to remember is that stress, if left unattended, can lead to depression.

3 - 10.7 Setting limits

The most important thing every caregiver must do is to set limits. You must know just how much you can do and how far you can stretch!

If you do not understand those limits and protect yourself, the likelihood of crashing is strong—and when that happens there is no winner. Include your feelings of guilt in knowing your limits, because they are a strong part of all you experience. They drive, you to or they prevent you from being your best.

Remember, none of us are at our best all the time. Life simply does not happen that way. However, we can use the tools and knowledge available to us to travel this new and difficult road and even have pleasure during the journey.

3 - 10.8 Have Realistic Expectations of the Situation

Knowledge is power, and nowhere is this more relevant than when we assume the position of being a caregiver. One must know about the disease that afflicts the elder. One must understand the prognosis, even if the future looks bleak. It is impossible to prepare for something unless one knows what to expect. If a nursing home is going to become an option look ahead and begin investigating them before the need arises. Good decisions are not made under panic. They are made with forethought and information.

3 - 10.9 Set Realistic Goals

Establishing boundaries is critical to the caregiver's success. No one should feel like everyone around them is trampling over them and their feelings. One must acknowledge that there are times when one must focus on his or her own life.

Sometimes you will be (or must be) unavailable to anyone but yourself or your spouse and children. Do not allow yourself to be sent on foolish errands when there are alternatives for accomplishing the errands.

3 - 10.10 Ask for Help and Accept It

People are generally good. Therefore, do not be afraid to ask them for help. Consider a case in point: if you simply cannot get to your mother's for her shot, perhaps a visiting nurse can take on your responsibility. When you are overloaded, ask a neighbour to stop and visit your mother, or try a non-medical home care and companionship service. You could perhaps take the afternoon off, go to the spa, or enjoy time with your friends. Most importantly, make a list.

All the people who can help you should be listed and itemized according to what kind of help they offer. Also make a list of the things that you believe need done and then issue requests for small tasks. Ask someone to pick up a prescription at the drug store. You will get willing assistants.

Do not allow the names to become jumbled in your mind—write them down. Lists are very useful. Listen to the discussions presented by other caregivers.

Very few issues are completely unique to you. Take what they have experienced and learn how to head off a potential problem or resolve one.

3 - 10.11 Above All, Take Care of Yourself

Taking care of you is the primary necessity of being a good caregiver. Make certain you are resting enough. Make certain, regardless of all the pulls upon you, that you take some time for a soothing bath, meditation time, a relaxing television show, and so forth. Everything that you put into yourself will also benefit all those around you who need your time and assistance.

3 - 10.12 The Role of Respite

It is important for caregivers to take breaks and temporarily leave their Caregiving responsibilities to other competent hands. Without that break, the loss of energy may create tension between the caregiver, the elder, and other family members.

Many families caring for older persons develop a pattern over time.

Usually, one family member (often a spouse or daughter) provides most of the care, becoming the primary caregiver. This person becomes increasingly stressed and burdened. This can continue for a long time until the primary caregiver experiences a crisis.

To avoid these problems, family members could meet to develop a long-term strategy which includes a list of small and large tasks divided into time, money, and labour categories. This helps everyone to share in the Caregiving responsibility.

Regular family meetings must also take place in order to discuss the condition of the person being cared for, as well as to renegotiate Caregiving responsibilities as needed. The caregiver could develop a network that includes support from both family and outside sources.

3 - 11 PLANNING TO BE A CAREGIVER

Planning experts will tell you that in order to succeed at something you need to have a plan. You must know where you are going, and how you are going to get there. Caregiving is no different. An action plan must be completed! An action plan can help you take control of your life, making you happy with yourself, and becoming a more effective caregiver. No two action plans will be the same. Everyone has different needs and wants. Take time to sit down and evaluate your own needs, emotions, and desires, then decide which actions you can take to alleviate some of the problems in your life. The following are some suggestions that experts feel could help you as a caregiver. Use the suggestions that would most suit you.

Suggested Guideline for Caregivers

I will:

- Seek help – any help that I can find
- Allow my family to help
- Involve my family in decisions
- Share the burdens of Caregiving with others
- Research, investigate, and stay informed
- Be prepared for the unexpected as well as the expected
- Try to understand and accept my own emotions, whether grief, anger, anxiety, depression, shame, or guilt
- Look for others who can understand my emotions
- Join a support group
- Recognize when I am in denial
- Accept my right to be emotional
- Accept my imperfections and flaws
- Forgive myself for my slip-ups
- Stop trying to be perfect
- Take care of my physical and emotional needs
- Keep up with activities that I enjoy
- Take things one day at a time, one crisis at a time, and one joyful moment at a time
- Make a plan
- Try to communicate with my care recipient, even when communication becomes difficult
- Try to find a good, caring doctor
- Set boundaries for myself and learn to say no
- Recognize when I am getting burned out, and seek help

You should also ask yourself the following questions with regularity:

- What would you like to add to the list?
- What specific needs do you have?
- What circumstances would you like to see changed?
- What kinds of plans would you like to have for the future?

Remember – When you begin to feel overwhelmed, pull out this action plan to remind yourself how you envisioned your life and your role to be.

3 - 12 FAMILY MEETINGS

When an elder has reached the point where they can no longer be independent, they suffer from a critical illness such as stroke, or have had an accident - a family meeting is needed. It is currently that the family must pull together, along with the spouse if he or she is alive and make important decisions about care for the elder.

The ideal situation would be to have any plans for disability, decline, or even death planned, when everyone concerned is able to make an educated decision.

Many professionals will agree that it is best to be proactive, instead of reactive

A crisis can bring a family closer together and illustrate strength and love, or it can drive a wedge of resentment between family members. If the issues come to a point of crisis, families—who are often spread across wide geographical areas—need to call themselves together to discuss the changes which are occurring and will occur in the future.

Stephen Covey, author of the 7 Habits of Highly Effective People, states: "Most families are managed based on crisis, moods, quick fixes, and instant gratification—not on sound principles. Symptoms surface whenever stress and pressure mount: people become cynical, critical, or silent, or they start yelling and overreacting."

If this is how you perceive a family meeting may progress, it is important to understand that it does not have to be so. You can have family meetings that are under control and structured. Understand that you will never be able to please everyone all the time. Remember that you are not meeting to satisfy your individual needs but those of your aging loved one.

Your first two family meetings should be only siblings or close family members who are in direct contact with the aging loved one.

Regardless of how you feel about your extended family members, it is imperative that over time, everyone is involved in the meetings. If meeting all together in person is not possible due to separation by distance, arrange for a conference call through three-way or conference calling.

The first meeting may take place without your loved one present, as topics may be discussed which could cause him or her to become upset. During the meeting, you must take a serious look at the situation at hand. It is best if everyone has prepared three or four concerns (and even possible solutions) to discuss beforehand. Together, you will need to begin planning and, if needed, take responsibility for specific duties. The goal of the first meeting is to create a plan of action to work together as a team, or if nothing else, call a temporary truce to a family feud.

Do not be discouraged if your first meeting does not run smoothly. Everyone involved will view the situation from a different perspective. Human nature is rather egocentric; do not be alarmed if most are concerned with how the changes will affect them.

If you will be discussing a topic that is going to be heated, it is best to hold that subject until another meeting where a neutral moderator can be present. For topics that will cause irrational responses, it is best to have all parties prepare, in private, why they feel so strongly about the issue. You may find you all have a similar fear and are simply reacting in different ways.

3 - 12.1 The Actual Meeting

As with all high-level negotiations, deciding where to hold the meeting is as potentially controversial as the meeting itself. Whether you hold it in an office, a restaurant, or in someone's home, keep in mind that you should select a setting that most of the participants will find comfortable.

Consider convenience, and potential distractions (e.g., noise, small children who need attention, etc.), when selecting a location.

A successful family meeting gives everyone a chance to be heard. All feelings are appropriate and need to be expressed and acknowledged. People will be more willing to talk about their feelings regarding the situation if they do not feel threatened.

For example, the brother who is never present may reveal that he is unable to stand seeing someone sick, and the sister who is doing all the work may not realize how she pushes others away when they offer to help.

Another sibling may be having marital problems, which he or she has not yet shared with the family. Another might be worried about losing a job. Each person needs to balance his/her own fears, concern, love, and desire to help with available time, strengths, weaknesses, and hopes.

Until the depth and breadth of the issues concerning the ill family member are explored, it is important to not try to solve the problems. Making a list of the problems as they are shared, however, will be useful during the problem-solving portion of the meeting.

It is important for each family member to learn to use "I" messages, as well to say, "I need..." rather than "you should…." Even when disagreeing, try to find a part of what is said that you can agree with. The goal of the meeting is to work as a team in caring for the person who is ill, even if there is conflict among family members in other areas.

At the conclusion of the meeting, make sure everyone has a clear understanding of the issues and considerations discussed. When the solutions to issues have been established, make sure that each person understands what he/she has agreed to do.

The most important thing for family members to remember is that the meeting is not a one-time event. Family meetings must take place regularly. It is helpful to schedule them at a given time, perhaps at the same time each month. However, if this is not possible, the meetings need to take place when the Caregiving situation or other situations in the lives of the family change. Holding regular meetings puts less pressure on family members to get everything resolved in just one meeting and allows more time to process the information and make decisions. When a family member is unable to attend a meeting, keep in touch with them by phone, mail, or email.

3 - 12.2 Who Should Attend?

Each family is different. In some families, only a husband/wife and their children are considered "family." In others, aunts, uncles, cousins, current and ex-in laws, and even close friends may be included in the definition of family. When planning a family meeting, it is important to include everyone who is or will be part of the Caregiving team and this may include a family friend, neighbour, or paid caregiver.

It is also sometimes helpful to engage the help of an outside facilitator, such as a social worker or minister, to help the family communicate about difficult subjects during the meeting. You may ask your loved one’s legal or religious advisors to be present at a family meeting to serve as facilitator or moderator. Geriatric care managers are usually skilled facilitators or social workers that can lend experience and balance to difficult family dynamics. It may be a good idea for the family members to chip in for the care manager’s fees, rather than having one member assume this responsibility.

A decision must also be made about whether to include the ill family member in the meeting. Family members usually do not want to be excluded from family events and their preferences for care must be considered. However, if someone has dementia or another condition where he or she might misunderstand the purpose of the meeting, it might be appropriate to hold at least the first meeting without him or her present. In addition, other family members may need to share with each other thoughts or feelings that would be painful for the ill person to hear. Consider holding one meeting to focus on those matters and holding a second meeting with the ill person present.

3 - 12.3 Potential Challenges

Families come with a history—a history of how each person relates to the others, a history of what role each person has played and currently plays within the family, a history of how each person feels toward the person who is sick, and a history of how each person deals with illness and adversity. Additionally, in each family there are rules about what can and cannot be said and what emotions are acceptable to express. These factors can make family meetings difficult. For this reason, a third-party facilitator can be helpful.

Family members play roles based on their positions in the family, their relationship to the person who is ill. One person may be the main caregiver, while others may handle finances, gather information, make decisions, and research medical facts.

One person might also play multiple roles. Also, often someone is the "blamer" and someone else the "blamed." One person may try to make peace, and another may try to sabotage the process. There will be secrets, old family rivalries, guilt, unequal burdens, differing investments, values, and interests. Some will worry about past promises and about someone else not pulling his or her own weight.

Everyone will need attention, power, love, control, and appreciation. It can help to acknowledge that there is likely no fair distribution of work and attempts to make it even between family members may fail.

A narrow focus for each meeting can help alleviate some of the pitfalls. Still, you will have to deal with some of the difficult issues when they get in the way of cooperation.

Remember that you cannot resolve long-standing family issues with one such meeting. The task is not to fix the family, but rather to bring everyone onto the same team, as much as possible, in caring for the ill family member.

If alcohol will detract from the focus of the meeting or could lead to conflict, it is better not to offer it. However, each family has different ways of communicating, and in some families, a drink may make everyone more comfortable and more amenable in the discussion. In any case, over-consumption should be avoided.

3 - 12.4 The Agenda

Communication is the key to working successfully with a group of people. If it is difficult for some family members to travel to the location of the meeting, technology can help: a conference call or the use of a Speakerphone can make it easier for them to participate. Video or audio recordings of the meeting can also be sent out to all family members who are unable to attend. With the use of email, even those who are not nearby can also be kept up to date on how things are going.

Before a meeting, you will find it very helpful to prepare a structured agenda. Someone in the family will generally introduce the idea of a meeting and arrange the date and location. That person can also create an agenda for the meeting and send it out to all the family members prior to the meeting date. Family members can then share their ideas and suggest additional items for discussion.

An agenda can include such topics as:

- The latest report from the ill person's physician
- Sharing of feelings about the illness/Caregiving

The agenda should also address fears:

- About death and dying
- About being overwhelmed
- About what will happen to family members after the death
- Sadness, confusion, anger, guilt, and shame
- What does the person who is ill want and need?

Daily Caregiving requirements must be on the agenda as well:

- Should the sick person move in with a family member?
- Does he or she need to be in an assisted living facility or nursing home?
- How much time does each family member have to visit?
- Are there other ways each person can help? Is other help available?

Financial, legal and medical resources will need to be discussed:

- Can someone be hired to help with some tasks and activities?
- What can other family members do?
- Are friends and neighbours available to help?
- Is respite care or day care an option?
- What is the caregiver willing to give up for the care recipient?
- What is the care recipient willing to give up for the caregiver?

Some of the financial matters - which should be discussed during family meetings include:

- How much will care cost?
- How much work can family members afford to miss?
- What financial help might be available from outside?
- Who will make decisions (e.g., financial, medical, hiring a caregiver, etc.) and how will they be made?
- What support role does each person want to play?
- What sort of support does the primary caregiver need?
- Discuss the need for respite (a break from Caregiving).
- Discuss help with meals, shopping, cleaning, laundry, etc.
- Determine how to find emotional support by telephone or email.
- Bring up help with chores, i.e., taking the care recipient to doctor's appointments
- How will the Caregiving and support needs change as the illness progresses?

At the conclusion of the meeting the following should be done:

- List the tasks that need doing daily, weekly, monthly, etc.
- Summarize the meeting and schedule for next one
- Distribute a written summary of what each person has agreed to
- Establish an email or telephone tree for regular updates.

While much of the above discussion focuses on the needs of the caregiver, the flip side of the coin is that it is not easy being a care recipient either. Always having to depend on someone else to do daily tasks can be demeaning and depressing. Added to the foregoing is the fact that the individual may have so many needs that it could be difficult to prioritize which ones are most pressing.

Although a Caregiving relationship is often based on love and concern, it can also be in tandem with conflicting emotions and needs.

3 - 12.5 The Needs and Wants of the Care Recipient

By asking the care recipient about their needs and involving them in what their needs and wants are, the best course of action can be determined.

- What does the care recipient want?
- What kind of situation can the care recipient accept?
- What kind of care does the elder's medical and/or mental condition require?
- What would make the care recipient happy?
- What are the basic rights of the care recipient?
- How does he or she feel about his or her condition and care?

With any relationship, there must be compromise, and, therefore, imperfect solutions. The solutions that all parties come up with might be just the best that can be done.

It will probably be difficult to cover all these issues in one meeting, so additional meetings will likely be necessary. Each ensuing meeting should have a clear timetable and a definite beginning and ending time. Be sure to stick to the timetable; if meetings get to be too long, fatigue sets in, minds will wander, and people may resist coming to future meetings.

3 - 12.6 Meeting Tips

Building Consensus

There are several win-win situations possible and your team must strive to reach them.

Not all the issues inherent in Caregiving and decision-making can be solved; sometimes it is important to accept approximations of a good solution. Try to work toward consensus building. Change happens slowly, but when families meet regularly, the seeds that are planted can grow into solutions that are more productive.

Often things do not change until there is a crisis, but the work that has been done during the family meeting will make decision-making easier when the crisis arise.

Agreements can be made on a time-limited basis to see if the agreed-upon action will work. Future meetings can be used to evaluate these trials and revise them, as necessary.

Respecting each person's individuality and situation helps to create an atmosphere of acceptance and allows for creative solutions to problems.

As a hypothetical case example, consider Carol's situation. Carol finds it difficult to be around sick people, so when her brother got lung cancer, she knew she could not take care of him. However, she was more than willing to make the pastas of their native Italy and take them to him to comfort him during his illness.

Consider a couple of additional cases. Jesse lives a thousand miles away but can get time off from work to be with her mother while her brother and his family take a vacation. When Ed's mother had surgery, Ed arranged to take care of his father with Alzheimer's, while his sister worked full time and helped with the expenses.

Another case is Gina's. She takes her parents to medical appointments while her sister makes sure they use their medicines properly every night.

Compromise

For solutions to work, people must learn to compromise. By being open to alternatives, you might get a part—though maybe not all—of what you want to achieve. We often hold out for only one solution to a problem. We do not consider other possibilities that could assist us. Asking for help is one of the hardest things to do.

Learning to graciously receive help offered could also be a struggle, not only for the person who is sick, but also for the person who is the primary caregiver. Being appreciative is the best reward you can give someone who is trying to help you, even if the type of help he or she offers is not exactly what you need.

When you make someone feel good about helping, he or she will likely want to help again. "Thanks, and gratitude" will take you a long way in working together. In creating the Caregiving team, think about how each person should be acknowledged.

Put It in Writing

A written agreement capturing the decisions and agreements made at the end of the meeting can be a helpful reminder for family members. Distributing a calendar with different days marked with responsibilities and commitments can help each person honour the agreements made.

Some Points to Remember

All participants must acknowledge and remember that they are in a meeting. Every meeting should have rules and guidelines.

Unfortunately, when it comes to family meetings, many do not recall this fact.

At the beginning of each meeting, gently remind all parties to have respect for one another and follow some rules that you have all agreed upon. If your family works smoothly and in unison, then focus on exploring your loved ones concerns rather than your own is achievable.

Meeting Rules

No one is to be allowed to dominate the meeting. If necessary, a timer can be used to give each family member 10 minutes to state their concerns and points of view:

- Create a list of all concerns then, as a group, rank them 1 through 5. One being the most urgent, five being the least. Tackle each one in the order of urgency, not in the order of preference.
- When someone is speaking, others must not interrupt. You would not interrupt another co-worker in a board meeting. Give your family members the same respect. If you have a comment, write it down and discuss it either at the end of their turn, or the beginning of your own.
- The facilitator or leader should be fair, but firm, to ensure that the meeting follows the agenda and does not take too much time.
- Use only "I" statements. Avoid finger-pointing accusations that begin with "You." This requires a conscious effort, and it may help to write a note as a reminder...
- Remember that your loved one still has the right and the responsibility to make his or her decisions (unless incompetence or dementia is the issue).
- Stick to the topic. It is easy to get off topic and revisit old family arguments. Keep the topic of the meeting posted where all can see it, whether on a central board or on the top of everyone’s note sheet. This is also difficult to master, but possible.
- Reach a sense of closure on each item of the agenda, or at least set an action item or next step. You may need to address issues that arise during the meeting and put them in a "parking lot" to be addressed later.

At the family meeting, everyone in attendance should agree on what to discuss at the next meeting and schedule a time and date prior to concluding. Doing so will help to avoid confusion.

3 - 12.7 Roles and Responsibilities

Once solutions and duties have been agreed upon, you should discuss the possibility of having a family spokesperson. This is especially helpful for those families who are in different areas of the country or the world. It is less complicated when there is a single point of contact for information.

Having a family spokesperson is also a way to encourage effective communication, avoiding the operator game. The operator game is when one person passes an original message on to another and this person now sends what they heard onto the third person, etc. By the time the last person is reached, the original message is distorted. This can cause major problems within a family.

The spokesperson will represent the family if your loved one is unable to confer with professionals. She/he will keep in touch with the doctors and relay the information to the other family members. Additionally, the spokesperson may have a responsibility—or shared responsibility—for health care and legal decision-making.

Care management duties should also be divided. Even if some live far away, they can contribute by calling your loved one, sending them cards, handling some paperwork, or even paying the bills. If someone else has small children and lives nearby, they could cook an extra serving of dinner and bring it over.

Another family member could be responsible for coordinating the services needed while your loved one remains at home.

It is inevitable that one person will shoulder most of the duties, but if all are participating as a team, the chance of resentment building is decreased. Talk to your family members and see about coordinating respite and vacation times so that you are not overburdened.

When necessary, bring in the appropriate professionals. These include geriatric care managers, elder lawyers, financial planners, counselors or religious advisors, and insurance professionals. Consider having family members contribute to a fund to pay for in home care assistance and respite workers.

3 - 12.8 Following Up on Family Meetings

After the first one or two meetings, your family will have found a style that works best for those involved. It is now time to begin discussing possible solutions. Include your loved one in the meetings if they can comprehend what is happening. Make sure to listen to the loved one first.

Allow the loved one the time required to express their concerns, wants, and desires. Do not degrade their concerns.

Although their priorities may be different than yours, unless doing as they wish will put them in physical harm, do your best to accommodate their wishes.

For example, the family might feel that it is best for "Mom" or "Dad" to move into a residential facility because there they will have meals provided, laundry cleaned, and opportunities for socialization.

A parent may wish to stay in their home for now because that is where they feel safest. Hiring in-home care assistance for a few months may be the compromise for both sides. Your loved one has usually lost much control over their life, and perhaps even their body, by the time you are holding a family meeting. Be gentle with them. It is upsetting for them to watch their world slip away and not have a say in what is happening or to see discord in their family.

3 - 12.9 Making It Work

By conscientiously planning, conducting, and following up on family meetings, members can assure themselves that they are working in the best interests of their loved one and minimizing unhealthy family dynamics. Remember that you are working for someone that has lost some capacity to handle his or her own affairs. Be a positive participant.

3 - 12.10 When Do You Need Outside Help? Where Can You Get It?

Although family meetings can be powerful and effective ways to connect and work with family members, they cannot magically solve all the problems of caring for an ill family member. When families have trouble working together or coming to agreements, or when the family is divided on a serious issue, it often helps to invite a neutral outside facilitator to attend. Sometimes a crisis precipitates the need for a meeting. For instance, if someone is in the hospital and major life and death decisions need to be made. Time can be of the essence. Whatever work you do together earlier will help you in these times of extreme stress.

Social workers from local caregiver organizations, as well as ministers, private case managers, social workers in home health or hospice, physicians, and discharge planners in hospitals and nursing homes can all help facilitate a family meeting or refer you to someone who can. Psychotherapists in private practices are trained in family counseling. If the caregiver finds him or herself in a difficult position, they might also want to see a psychotherapist privately. Do not forget the support the caregiver can find with friends, colleagues, and support groups. Sharing experiences with other caregivers can help ease the feelings and frustrations often involved in being a caregiver.

3 - 12.11 Family Choices Involve a Systematic Process

When the family meeting to determine caregiver issues is completed, look at the following to see if all areas were answered to the benefit of all.

Identify the Problem

Few problems allow us to make neat and simple choices among clear alternatives. We often must stop and ask ourselves: Is there a problem? Whose problem is it? How many problems are involved?

Determine the Goal

Next, ask why you are making this decision in the first place. What should happen as a result? Realize that your goal may change as you get more information about the problem. Remain open to new possibilities.

Consider the Alternatives

Brainstorm all the ways you could reach your goal. Collect the information you need about each option. Do not discard any possibilities at first; sometimes the most unusual alternatives yield the best results.

Consider the Impact

Consider each alternative. What would happen if you adopted it? Would the outcome be consistent with your values and the values of others affected by your decision? Do any of the alternatives require resources you lack?

Choose an Alternative

Once you have collected information, consider your own values and the possible consequences of each alternative. Pursue the solution that seems to give you the best opportunity to reach your goal.

Evaluate the Outcome

Did you reach your goal? Does the solution feel comfortable? Does it create new problems? If the solution does not work, do you start over from the beginning, or can you modify your decision to produce a more useful result?

3 - 13 ELDER ABUSE AND NEGLECT ISSUES

Caring for another person can be one of the most rewarding and challenging jobs that a person will ever confront. Caregivers may wonder how they will balance all the demands of family, work, and now caring for another person.

Will there be enough hours in the day to do all the things that must be done? If something must give, what should it be? The caregiver may wonder if they are being fair to their family. They may be at a loss as to what to do.

Often caregivers consider what they can or should do for others while neglecting themselves. When they do this, the stress can build leading to actions that would not normally occur. The caregiver may yell or even hit. Is this abuse? What are other ways of dealing with frustration or stress?

Abuse is not a normal reaction to stress and most caregivers, even in extremely stressed situations, will not resort to it. It is, however, important to understand what abuse is and how to prevent it.

3 – 13.1 Physical Abuse

Physical abuse is defined as the use of physical force that may result in bodily injury, physical pain, or impairment. Physical abuse may include, but is not limited to, such acts of violence as striking (with or without an object), hitting, beating, pushing, shoving, shaking, slapping, kicking, pinching, and burning.

In addition, the inappropriate use of drugs and physical restraints, force-feeding, and physical punishment of any kind also are examples of physical abuse.

Signs and symptoms of physical abuse include but are not limited to:

- Multiple bruising, not consistent with a fall
- Black eyes, slap marks, kick marks, grasp marks
- Burns, such as cigarette burns, dunking burns
- Fractures not consistent with falls
- Stench of urine or feces
- Indications of malnutrition or over-feeding
- Inability of the elder to explain injuries
- Missing hair

3 – 13.2 Neglect

Neglect is defined as the refusal or failure to fulfill any part of a person's obligations or duties to an elder. Neglect may also include failure of a person such as a caregiver who has fiduciary responsibilities to provide care for an elder (e.g., pay for necessary home care services). Another example is the failure on the part of an in-home service provider to provide necessary care.

Neglect can also involve withholding such life necessities as food, water, clothing, shelter, personal hygiene, medicine, comfort, personal safety, and other essentials included in an implied or agreed-upon responsibility to an elder.

Signs and symptoms of caregiver neglect include but are not limited to:

- Lack of basic care
- Abandonment
- Over medication
- Not providing proper food or fluids
- Failure to provide proper health care
- Lack of personal care
- Not dressing someone
- Not dressing someone appropriately
- Refusing to buy new clothes for someone who has gained/lost weight
- Being left to sit in urine/feces
- Absence of mobility aids so the person's movements are restricted
- Absence of necessary medication
- Improper fitting or damaged dentures
- Non-functioning hearing aids, including lack of batteries
- Isolation, lack of social contact
- Rashes, bedsores, lice
- Caregiver blames the elder for injuries

3 – 13.3 Sexual Abuse

Sexual abuse is defined as non-consensual sexual contact of any kind with an elderly person. Sexual contact with any person incapable of giving consent is also considered sexual abuse.

It includes, but is not limited to, unwanted touching, all types of sexual assault or battery, such as rape, sodomy, coerced nudity, and sexually explicit photographing.

Signs and symptoms of sexual abuse include but are not limited to:

- Inappropriate touching
- Fondling
- Inappropriate kissing
- Oral contact
- Genital contact

- Digital penetration (vagina or anus)
- Rape (vagina or anus)
- Penetration with objects
- Exploration
- Pornography – forced to participate, watch it, etc.
- Ritual/satanic abuse
- Initiating unwelcomed talk about sex
- Proposing unwelcomed sexual contact
- Bruises and bleeding in the genital area
- Venereal diseases
- Genital warts

3 – 13.4 Financial Abuse

Financial exploitation is the taking or misuse of the vulnerable adult's property or resources by means of undue influence, breach of fiduciary relationship, deception, harassment, criminal coercion, theft, or other unlawful or improper means. Indicators of financial abuse:

- Cash is stolen
- Benefit/pension is cashed and not given to the elder
- A person says that something cost more than it did
- A person with power of attorney withholds money
- Money is withheld – not enough money to buy food, pay bills, rent, etc.
- People say they are paying for things, but they are no.
- A person is persuaded/forced to transfer money
- An elder denied residential care
- Unusual banking, including large withdrawals
- Reluctance to discuss financial matters
- Numerous unpaid bills
- Caregiver more focused on money than on care
- Poor clothing and household conditions

3 – 13.5 Emotional Psychological Abuse

Emotional or psychological abuse is defined as the infliction of anguish, pain, or distress through verbal or nonverbal acts. Emotional and psychological abuse includes, but is not limited to, verbal assaults, insults, threats, intimidation, humiliation, and harassment.

In addition, treating an older person like an infant; isolating an elderly person from his or her family, friends, or regular activities; giving an older person the "silent treatment," and enforced social isolation are examples of emotional and psychological abuse.

Signs and symptoms of emotional/psychological abuse include but are not limited to:

- Humiliation
- Intimidation
- Ridicule
- Causing fear/mental anguish/anxiety
- Threats/threatening behaviour
- Bullying
- Verbal abuse (e.g., shouting, swearing)
- Harassment
- Isolation/withholding social contact
- Denial of basic rights (e.g., choice, opinion, privacy)
- Depression, suicidal behaviour
- Cowering, evasive eye contact

3 – 13.6 Self-Neglect

Self-neglect is the inability or lack of desire by the vulnerable adult to maintain and safeguard his or her own physical and/or mental health. It is important to remember, however, that often older adults are dealing with limited resources that may limit their ability to fully care for themselves.

Self-neglect generally manifests itself in an older person as a refusal or failure to provide himself or herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated), and safety precautions.

The definition of self-neglect excludes a situation in which a mentally competent older person, who understands the consequences of his or her decisions, makes a conscious and voluntary decision to engage in acts that threaten his or her health or safety as a matter of personal choice.

Indicators of self-neglect:

- Refusing needed assistance
- Not taking medications as prescribed
- Not eating for proper nutrition
- Home in disrepair or dirty

3 – 13.7 Who Is Abused

Anyone may find themselves in an abusive situation, but some people are more vulnerable than others. It is estimated that two-thirds of all victims of abuse are female and over the age of 78. That means that a third of all people who are abused are male. Abuse knows no gender or age limits.

While there is no set pattern of who will be abused, there are certain characteristics that make someone vulnerable. Often the victim is a female who lives alone but relies on others to provide some cares. This person has recently experienced a decline in physical or mental health, which has led to an increase in stress. In addition, often the person has had a recent change in their economic conditions, usually a decrease. It could, however, include a financial gain. A key component is the change in the relationships and roles.

3 – 13.8 Who Are the Abusers?

Again, anyone who finds himself or herself in a stressful situation may say something or act in a way that could hurt another. Most care providers do not abuse. It is important that when we find ourselves in that situation we stop, take a deep breath and try to find a more positive way to respond.

Some people have grown up in an abusive situation or learned abusive behaviour that drives their reaction to others. The following provides a list of the greatest risk factors for causing abuse:

- Under the age of 60
- Most often a relative
- Often has a history of mental illness
- Had a recent decline in mental health
- Abuses alcohol
- Often the primary caregiver
- Often lives with or has access to the adult they abuse
- A prior history of violence

The reasons for abuse are as varied as the people who abuse. However, there are certain situations that are more likely to trigger abuse.

Stress is not a cause of abuse but can intensify any problems. If a caregiver is not sure when stress is greatest for them, it may be helpful to prepare a journal for at least two weeks. Then re-read the daily journals paying close attention to times when stress was present. Then look for patterns. Then look for ways to reduce the stress before it occurs. This could include going for a walk or to a different room or asking someone to take on the care giving for a time. Caregivers should also ask for help. It takes strength to know when it is not possible to do it all alone.

3 – 13.9 Tips for Caregivers

Many countries have passed elderly abuse laws. These laws bind caregivers in two ways: not to abuse the elder person (physically, mentally, or monetarily) and report any incidents of abuse or suspected abuse.

As a caregiver, a person must provide a clean and safe environment, nutritious meals, and clean bedding and clothes.

Caregivers who oversee an elder's finances must also use that money properly, purchasing necessary services for the benefit of the person to whom care is given.

Failure to provide care, failure to get care, and failure to purchase care are all forms of abuse or neglect.

In addition, caregivers may not physically, sexually or psychologically abuse the person receiving the care. Yelling, screaming, withholding affection, etc., is as much an abuse of the person as is striking the person with an object.

Caregivers must be ready to accept the physical, psychological, and legal duties to provide the necessary care.

All segments of the family are affected by family violence, according to the newest statistical profile of family violence in Canada. Parents assaulted children, both men and women assaulted their spouses, and even the elderly were victims of their children.

Elder abuse is a problem that many people want to ignore and deny, but everyone involved needs to take responsibility to help prevent this crime against the elderly. Every year thousands of elders in are victims of some form of abuse.

A professional caregiver or a family member may be the source of this abuse. If there is ever any doubt about an elder's safety, contact the proper authorities immediately.

In 2007, Statistics Canada reported that the overall rate of police-reported violence against seniors increased by 20 per cent between 1998 and 2005.

Seniors are the least likely demographic to suffer violent crime, but they are most at risk of suffering violence at the hand of a family member. For those over 65, 47 out of every 100,000 women were violently assaulted by a family member, according to 2005 statistics. For men over the age of 65, the figure was 36 cases per 100,000 people.

3 - 13.10 Preventing Elder Abuse

Elder abuse is a crime and it should be reported and stopped. Putting an end to the abuse is the most important thing. The police will help. What happens in another's home is everybody's business when it involves elder abuse.

Most instances of elder abuse occur in families that have an abnormal amount of stress. Reducing the stress within families caring for an elderly person is a good way to prevent elder abuse.

People must be aware that elder abuse is a serious problem and taught to understand that some behaviour reserved for the elderly person under another's care is unacceptable and may be criminal. Elders must be made aware that this type of conduct toward them is criminal and unacceptable. They should also know that it will result in the laying of criminal charges against the abuser.

Many abused elders are afraid that reporting their family member would ruin that person's life; they should be reassured that this is not the case.

Listen and talk with elders. If you have any suspicions, broach the subject of elder abuse with them and give them references to law enforcement or social service resources in your community. Abused elders are often isolated from the community and your contact with them alleviates this condition.

There are laws in many jurisdictions, which make it mandatory to report elder abuse. Many nursing homes have such policies, adding that no employee can lose their job because they report a case of elder abuse.

3 – 14 CAREGIVER REWARDS

There is much documentation that Caregiving provides benefits not only for the receiver, but also for those providing the care. With demands on elders' informal care networks unlikely to subside in the coming years, it is encouraging to learn that many Canadians look favourably upon these needed duties.

Caregivers usually feel a responsibility and an obligation to help an older family member.

Husbands and wives who care for spouses often feel that Caregiving is part of the responsibility they accepted when they were married, and that it is an expression of love for their mate. Husbands may feel a need to express gratitude to their wives for the support and devotion given to the home and family in the earlier years of the marriage.

While there are tasks, responsibilities, and potential for stress in the Caregiving process, there may also be rewards. Research has documented and validated "burdens" associated with Caregiving, especially for those caring for persons with dementia.

However, studies have also suggested that positive benefits, such as improved relationships, satisfaction from doing a job well, fulfilling a duty or obligation to the care recipient, enhanced knowledge of another person, or heightened sense of value and self-esteem, may result. Caregiving in some cases may offer a purpose and compensation for lost careers or losses of loved ones.

The time of caring for an older parent or relative can be one of joy and enrichment. It can be a period of increased sharing, a renewal of that special closeness that has perhaps slipped away over the years, or a time of rediscovering the family history.

It can be a time for the healing of those old wounds left festering from childhood or adolescence. It can be a time for renewing old friendships or gaining wisdom from an elder. Many caregivers report that providing care makes them feel useful.

Many anecdotal reports attest to caregivers' satisfaction knowing that their older relative is receiving help while remaining in the community. For many caregivers, the giving of assistance is not a one-way street. Rather, it is part of a mutual aid pact, as approximately one fourth of caregivers’ report that the older person for whom they care helps financially or assists with household chores.

Couples can be drawn closer together through the expression of love and the fulfillment of the marital commitment to care for the partner “in sickness and in health.” Caregivers who master new tasks feel an increased sense of confidence and self-worth, as when men learn to cook, and women learn to make home repairs.

Adult children who are caregivers usually help their parents willingly and feel satisfaction and a sense of accomplishment from doing so. Children may develop a more intimate relationship with their parents while sharing time and providing care.

Parents may express more appreciation of their adult children than they had in the past, and children may strengthen their relationships with brothers or sisters who are assisting. The Caregiving situation can provide both parent and child with an opportunity to resolve longstanding conflicts during the last months of the parent's life.

3 - 14.1 Rewards and Joys of Caregiving in a Nutshell

- A renewed relationship with the person being cared for
- A chance to give back, a sense of accomplishment
- Development of new skills and knowledge, e.g., advocacy abilities
- Increased compassion, growth, and new relationships with others through support groups
- The building of memories

3 – 15 CONCLUSIONS

Caregivers may find themselves always thinking about everyone else (i.e. their aging relative, their children, their spouse, etc.). They are the last person that they ever think about (if they think about themselves at all). The constant care that they give others is putting them in danger of losing their sense of self-esteem.

Experts believe that the more time the caregiver spends thinking about himself or herself and boosting their own self-esteem, the better care that they can provide others. This is no secret, as the person with little self-esteem can provide very little useful help to others.

It is important that the caregiver protects their own sense of value, worth, and self-esteem. A caregiver must ensure that their needs are being met, not only those of the care recipient.

Remember the Guidelines to follow for a successful Caregiving experience:

- Remember your interests
- Do not be consumed by Caregiving
- Take a break

When caring for others, do not neglect your own needs. A wise old saying teaches: "Don't kill the healthy chicken to make soup for the sick one."

3 - 15.1 Canadian Caregiver Coalition - A National Resource on Caregiving

A national conference on Caregiving, sponsored by Social Development Canada, was held in Gatineau, Quebec on October 17-18, 2005.

The conference highlighted a few challenges for caregivers and the organizations supporting them, and recommended areas for action.

- **Recognition and personal support for caregivers:** Caregivers need to be recognized as partners in care, through awareness-building and discussing their role with health care and service providers. For Caregiving to be sustainable, caregivers need a combination of personal support networks and community-based supports.
- **Planning and preparation for caregivers:** Health care and service providers need to prepare caregivers for their role by informing them about issues such as the care receivers' health condition and legal and financial matters. Creating positions of caregiver advisors who are involved at the start of the Caregiving journey would assist caregivers in connecting with the necessary resources.
- **Partnerships:** Community-based organizations need time and resources to nourish linkages and partnerships with other community organizations, and with governments, service providers, and other relevant associations. Partnerships enable organizations to provide better supports to caregivers, as well as encourage more dialogue and engagement with the policy agendas affecting caregivers.
- **Supporting diverse groups of caregivers:** Community-based organizations have had difficulty providing supports to certain groups of caregivers, including First Nations, Métis, and Inuit communities; immigrants; refugees; people living on low incomes; and those living in rural or remote regions. Caregiving organizations need to engage more with community groups already serving the community to develop strategies that better meet their needs. A challenge that needs attention is the barriers that immigrants and refugees face in trying to access supports through the health care system.
- **Stable funding:** Community organizations at all levels require stable sources of funding and not just project-based funding, if they are to continue their work supporting caregivers. Community organizations are being asked to assume greater responsibilities for providing services without a corresponding transfer of funds, and this "offloading" can be difficult for them to manage.

3 - 16 REFERENCES

Portrait of Caregivers 2012, General Social Survey, Statistics Canada

Canadian Study of Health and Aging Working Group, Canadian Journal on Aging, 1994

Caregiver abuse, neglect and exploitation, North Dakota State University, 2003

Caregiver Network Inc. (CNI) – Ms. Karen Henderson, Toronto, ON

Caregiving Families Newsletter, 17 Applegate Ct., Madison, WI 53713

Caring for an Aging Society, Analysis of GSS 2002 by Kelly Cranswick, Statistics Canada www.statscan.ca

Canadian Caregiver Coalition www.ccc-ccan.ca

ElderCare Online, www.ec-online.net

Family Caregiver Alliance, 690 Market Street, Suite 600, San Francisco, CA 94104

The 5 Stages of Family Caregiving, Dr. Mark Frankel, 2010

Health Canada and Statistics Canada - statistics on Caregiving

Kelly Cranswick, analyst with Housing, Family and Social Statistics Division, Statistics Canada

National Alliance for Caregiving

North Carolina Department of Health and Human Services, Division of Aging 1997/98

Olga Malott, a gerontologist at Ontario's University of Waterloo

This page intentionally left blank

Chapter 4

End-of-Life Planning Issues

---

4 – 1 KEY OBJECTIVE OF THIS CHAPTER

This chapter is designed to give you a broad perspective on a wide variety of end-of-life issues - from the mundane (paperwork, notifications, checklists) to the gut wrenching (pain management, deteriorating quality of life, and life and death decision making).

When it comes to end-of-life issues, there are no easy answers, no cookie cutter solutions - and pain and suffering, for everyone involved, can be part of the process. However progress has been made in assisting those who are dying in a humane manner.

There are benefits in learning about what to expect. Becoming familiar with the major issues that a critically ill elder will face is information that cannot help but be useful, both now and in the future.

4 – 1.1 How Will This Objective Be Achieved?

We will start by looking at a variety of the decisions and issues that present themselves immediately prior to death. From there we will take a close look at such things as:

- End-of-life health care
- Hospice/Palliative care
- Pain management and life and death decision making
- Health Care Directives
- Right to die issues

4 – 2 INTRODUCTION

The death of a loved one is trying and difficult at the best of times. When death is slow and painful - when there is virtually no quality of life at the end - it can become more difficult still.

Tough decisions need to be made in a myriad of fronts. Where should the death take place? What can be done to make the loved one more comfortable? What other matters should be addressed in advance of the death?

Worse, in some instances decisions will have to be made which are quite literally matters of life and death. Should heroic measures be taken? Should life supporting technology be discontinued? Is quality of life being sacrificed for quantity of life? What would the person who is dying want? Is medical assistance in dying something the patients wants?

Welcome to end-of-life planning.

4 – 3 ADDRESSING THE INEVITABLE

Many families struggle with the issue of what should be done when a loved one is close to death. There are no simple answers. Every situation is unique.

As difficult as it may be, one of the first things that the family should consider is an open discussion of what is going to happen.

Death is inevitable. It is also a subject that is almost universally avoided. Talking about a person's impending death is frightening and difficult, which leads many to put it off until later. Unfortunately, we cannot always predict what "later" will be. Although discussing death can initially be threatening, loved ones will want to understand an elder's final wishes, so that they can carry them out as fully as possible.

That said, raising the topic can be quite difficult. Here are some suggestions from the National Caregiver's Library:

- Do not push an elder to talk about death. He or she will do so when ready.
- Do not be offended if the elder chooses to discuss death with someone else. Let the elder know that you are comfortable discussing the topic when he/ she is ready.
- Always use language about death that everyone is comfortable using. Try not to avoid using the word, but feel free to use metaphors or softer words (e.g., passed away) in place of the word "death."
- Do not rush the conversation. Make time for the elder and wait until he or she feels comfortable.
- Do not discredit any emotions about death that the elder is feeling. Be sure to acknowledge that these may be influencing what you say or how you behave. This will help the elder to understand.

- If an elder brings the topic up and it scares you, do not shut him or her down by saying something like "don't say that." Instead, even if you are not ready to talk about it, let the elder discuss his/ her feelings. Keep the conversation going by saying things like "really?" or by rephrasing what he or she has already said.

- If you are ready to discuss death, talk naturally about what things will be like when the elder is no longer present. Ask if there are any special wishes with respect to future events that they will miss (e.g., Dad is there someone who you would like to designate as the "turkey cutter" next Thanksgiving?)
- Finally, talk about the elder's current condition and his/ her hopes or fears for the future. If there is a way to gain information that would lessen his or her fears.

Always remember, some days will be harder than others. If you have previously discussed death with the elder, but are uncomfortable doing so later, do not feel that you are failing. This works the other way around as well. If the elder has days when he or she has trouble talking about death, do not get upset. Just remember that while it is difficult to talk about, discussing death can ultimately alleviate fears and foster stronger emotional bonds between you and the elder.

4 – 3.1 When the End Is Near

Some elders may be frightened and have a strong desire to have a loved one close at hand as they approach the end. Others may simply want to be alone - and this may be quite difficult for the family. Often family and friends find comfort in reading, reminiscing, saying prayers, or singing, while others just want to be there, to share a few final precious moments.

The actual experience of watching a loved one slowly fade away - and the comings and goings of other family and friends - may even change a family member's wishes.

In a perfect world, family and friends should not spend much time on medical treatment decisions when a loved one is close to death. It is best to have had discussions of this nature much earlier on, so that as little time as possible is wasted on such matters. The focus should be on the loved one and spending as much quality time with him or her as is possible.

Sometimes families - or the elder who is dying - may have to remind any health care professionals involved that what little time may be left should not be consumed with blood tests, x-rays, other scans, or detailed advance directives (other than resuscitation orders). Remember, too, that this can be a good time to call on spiritual support, including clergy if that is a part of the elder's tradition or it is requested.

Music can also provide some needed support that may be beneficial to both the dying elder and the family.

When a loved one is close to death, family and friends may also want to say their farewells and, if necessary, to ask for forgiveness (assuming there are still some outstanding issues that have not already been addressed). Everyone who visits should also provide some comfort: remind the dying person that he or she lived well and is loved. This should be done even in situations where the person dying is asleep, or somewhat incoherent. Often, they are still able to hear. Saying these things to a person near death can also be comforting to the people who are left behind.

The actual process of visiting a person near death varies from family to family. Some will have a sequence of people visit, one-by-one, to say their own goodbye. In other cases, more irregular and unscheduled visits will be the norm. In some cases, families will want to incorporate religious rituals into the exercise. Take your cue from the patient.

4 – 3.2 The Time of Death

Just as doctors cannot pinpoint the precise day when a baby will be born, they cannot predict the exact day or hour when a loved one will die. This uncertainty can often be difficult for the family.

Some illnesses make predictions particularly difficult - with a range of possibilities that extends from hours to weeks. In other cases, it may be possible to be far more precise.

In addition, the signposts of an impending death are not simply physical in nature. There are also emotional-spiritual-mental signs and symptoms.

All these signs and symptoms will not occur with everyone, nor will they occur in this sequence. Each person is unique and needs to do things in his or her own way. The body prepares itself for the final days of life in the following ways:

Fluid and Food Decrease

There is usually little interest in eating and drinking. This can be hard for the family to witness and accept. Food is life and often the family has a hard time letting go. It is however in the patient’s best interest to ask for what is and is not wanted. Allow the person to eat and drink whatever is appetizing to them, but any nourishment should be taken slowly and in small amounts. Let the person decide how much and when to eat and drink. Be careful of decreases in swallowing ability, and do not force fluids if the person coughs soon after. Reflexes needed to swallow may be sluggish. Small chips of ice, frozen juices, or Popsicles may be refreshing in the mouth.

The person’s body lets him/her know when it no longer desires or can tolerate foods or liquids. The loss of this desire is a signal that the person is making ready to leave. This is not a painful process. Dehydration no longer makes them uncomfortable. Glycerin swabs may keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also be welcome.

Decreased Socialization

The person may want to be alone with just one person or with very few people. Speech is often slow or difficult or the person may not have the ability to speak at all. It is natural to not feel like socializing when feeling weak and fatigued. It can be disturbing to the dying person to have more than a few people in the room.

Think about taking shifts in order to be with the person but also keep the environment quiet and calm and reassure the person that it is okay to sleep.

Sleeping

The person may spend an increasing amount of time sleeping and become uncommunicative, unresponsive, and difficult to arouse at times. This normal change is due in part to changes in the metabolism of the body. Sit with the patient, gently hold his or her hand; speak softly and naturally. At this point, "being with" is more important than "doing for." Never assume that the person cannot hear; hearing is said to be the last of the five senses to be lost. Hearing may remain very acute although the person may seem asleep, so do not say anything in their presence you would not say to them when awake.

Restlessness

The person may make restless and repetitive motions such as pulling at sheets or clothing or have visions of people or things that do not exist. These symptoms may be a result of a decrease in the oxygen circulation to the brain and a change in the body's metabolism. However, studies in near death experiences are challenging this belief. Do not be alarmed or interfere or try to restrain such motions. Talk calmly and reassuringly with the confused person so as not to startle or frighten him/her further. Lightly massaging the hand/forehead, reading to the person, or playing soft music can also have a calming effect.

Disorientation

The person may seem confused about time, place, and identity of people around him/her, including close and familiar people. Identify yourself by name rather than asking the person to guess who you are. In conscious moments, the person may speak or claim to have spoken to people who have already died, or to see places not presently accessible or visible to you. This is not a hallucination or a reaction to medication. It signifies a person beginning a normal detachment from this life, preparing for the transition so it will not be frightening.

Accept this transitional time. There is no need to contradict, explain away, belittle, or argue about what the person claims to see or hear. Listen with respect to whatever the person has to say, allow free expression of feelings and offer comfort through touching and/or talking reassuringly and calmly.

Incontinence

The person may lose control of urine and/or bowels as the muscles in the area begin to relax. Diapers or incontinent pads may be helpful to protect the bed and assist in keeping the person clean and comfortable.

Urine Decrease

Urine output normally decreases, becomes more concentrated, and may become the colour of tea. This is due to decreased fluid intake and to a lessening of circulation through the kidneys. Any medical personnel present may suggest that a Foley catheter be inserted or irrigated.

Breathing Pattern Change

The person's usual breathing patterns may change with the onset of a different breathing pace. Breathing may become shallow, irregular, fast, or abnormally slow. A pattern consists of breathing irregularly with shallow respiration or periods of no breaths for 5–30 seconds, followed by a deep breath. The person may also have periods of rapid shallow panting type breathing. Sometimes there is a moaning-like sound on exhale; this is not distress, but rather the sound of air passing over relaxed vocal cords.

Changed breathing patterns are very common for a person nearing death and indicate decreased circulation in the internal organs and buildup of body waste products. This noisy breathing is often referred to as "death rattle." Elevating the head and/or turning onto the side may increase comfort. This change in breathing is not upsetting for the dying person. However, if family or caregivers find it unnerving, the doctor or nurse can help reduce the noisy sound by giving medication.

Congestion

Oral secretions may become more profuse and collect in the back of the throat. The person may develop gurgling sounds coming from the chest. These sounds can become loud and distressing to hear. These normal changes come from fluid imbalance and an inability to cough up normal secretions. It is helpful to raise the head of the bed or use pillows to raise the person's head so that the secretions pool low and will not stimulate the gag reflex. Turn the person's head to the side and allow gravity to drain the congestion. You may also gently wipe the mouth with a moist cloth.

Colour Changes

Due to changes in circulation the person's arms and legs may become cold, hot, or discoloured. This may be especially noticeable in extremities where the colour may change to a darker, bluish hue. This is a normal indication that the circulation is conserving to the core to support the most vital organs.

Irregular temperatures can be the result of the brain sending unclear messages. Keep the person warm if they appear cold, but do not use an electric blanket. If the person continually removes the covers, then allow them just a light sheet. Sweating may occur and there may be an odor resulting from the many physiological changes taking place in the body. The heartbeat and pulses may become slower, weaker, and irregular.

Permission to Go

When someone enters the last days of life their body begins the process of shutting down, which will end when all the physical systems cease to function. This is usually an orderly and non-dramatic series of physical changes that are not medical emergencies and do not require invasive interventions. These physical changes are a normal, natural way in which the body prepares itself to stop. This release may include resolving whatever is unfinished of a practical nature and seeking or receiving permission from family members to “let go."”

A dying person will commonly try to hold on, even though it brings prolonged discomfort, in order to be assured that those left behind will be all right. Or the person may be waiting on a relative that has not yet arrived. When the person is ready to die, and the family can let go this is the time to say good-bye in personal ways. It may be helpful to just lay in bed with the person, hold a hand, and/or say everything you need to say. Tears are a normal and natural part of saying good-bye, and do not need hiding or apology. Tears express your love and help you to let go.

At the Time of Death

It may be helpful for family members to discuss ahead of time what to do when the final moment arrives. At the time of death: breathing ceases, heartbeat ceases, the person cannot be aroused, the eyelids may be partially open with the eyes in a fixed stare, the mouth may fall open as the jaw relaxes, there is sometimes a release of bowel and bladder contents as the body relaxes.

The death of someone, although an anxious event for family and friends, is not an acute medical emergency. While you should call medical personnel, it is not necessary to call the medical examiner, the police, or 911. When the death has occurred, take the time needed to call a supportive person or to adjust to the situation. There is no rush. Taking care of you is what is more important now.

As noted above, it is difficult to determine exactly when death will occur. There is however a notable exception to this rule. If life support is being stopped, it is somewhat easier to predict when death will occur. The physician should be able to tell the family what to watch for in order to determine roughly how long it will be.

4 – 3.3 Being Present at time of Death

Many people feel that they should be present at the very moment when a dying loved one draws his or her last breath. Trying to be there can be quite draining, however, since the exact time of death is impossible to predict. People sometimes keep up a death-watch for days, and finally must get some coffee or some sleep. Often, this is when the person finally dies. Perhaps he or she was "waiting" or just needed to be "on his or her own" a little before letting go. Or maybe the timing was simply pure chance. If the family members are not present when the loved one dies there can be feelings of guilt. Offering reassurance that the loved one was not alone and was safe and secure can be helpful.

Important things are rarely said immediately prior to death, so it is not likely that survivors will miss hearing something of significance if they are not present. On the other hand, a few patients really do say some remarkable things in the days and hours ahead of their deaths. Some will attempt to comfort family and friends or make peace with respect to any outstanding matters. It can be quite important for the dying person - and the family - to hear these things and come to some resolution.

In most instances - no matter what transpires immediately prior to death - spending some time at the bedside is worthwhile. Families often use this time to share feelings and perspectives that they usually do not have the opportunity to discuss. They can also begin to sort out new relationships and do some practical planning as well.

Families and dying loved ones should give instructions to caregivers in hospitals and nursing homes about who should be called, if possible, when death is close, and who should be called when the person has died.

4 – 3.4 Confirming Death

Usually the person dying will take a last breath, sigh or shudder, and then die. Many people make another effort or two at breathing but are unable to move any air. A few will have some limb and/or trunk movement for up to ten minutes.

So how do we determine that the person has died?

If there is no air movement, then the person is dead. Keep in mind, there is absolutely no urgency in making this determination, so you can just sit and watch for a few minutes. Family and friends may even want to spend a few minutes crying, praying, or meditating.

Many of us are too unfamiliar with death to be comfortable in determining that it has, indeed, occurred. In a hospital or nursing home, a professional - who can check with a stethoscope - should be summoned. In a hospice or a home, a nurse can usually come within an hour or so.

If the death is at home, the family should not call 911, or involve the emergency rescue system in any way. Death is not an emergency.

To make matters worse, emergency technicians will often find it difficult to size up the situation - and just when the family needs comfort and time, they will find themselves in the awkward position of answering questions and explaining themselves to outsiders. It is far better to call the doctor's office or a hospice. Often it helps to have spoken to the doctor in advance, about what is going on.

Many people really need to hear someone else say that the person is dead. "Pronouncing" a person dead is important to them and it provides some closure. Even if it is perfectly obvious, the family should still be able to ask someone in authority "Is he or she dead?"

4 – 3.5 Decisions and Activities Just After Death

After a death, there are more decisions to be made and activities to be planned than most families expect. Usually within a few hours, someone will have to move the body to a location that handles the remains, such as a hospital morgue, a funeral home, or a government medical examiner's morgue. If death is to take place at home, arrangements of this nature should be made ahead of time. Immediately after death - or beforehand, if possible - discussions should take place with a funeral home as well.

The cause of death will also have to be determined. Usually the doctor decides this, but if the cause is multi-factorial or embarrassing, family members should talk with the doctor and negotiate a resolution. It also may be necessary to decide about having an autopsy.

Another important issue that needs to be resolved concerns death certificates. Even for small and uncomplicated estates, people often find that as many as two dozen is required. Families should get much more than they think they need, as it is often costlier and more troublesome to get them later.

There may also be some issues to deal with concerning whether organ donation is appropriate and desired. Organ donation (heart, kidney, lung, liver, and so on) can be arranged in advance or at the time of death. Tissue donation (bone, cornea, and so on) can often be arranged even hours after death. Donations of this nature can help others, fulfill the deceased's wishes and offer some comfort to surviving loved ones.

Immediately after death, it is also likely that many people will have to be notified. Many will require prompt notification to arrange airline, or other travel. Consider asking for some help - from friends, other family members or any professional caregivers involved. The family should also think about setting up some plans so that the people notified can contact others.

Some dependents may require immediate attention. Any dependent children as well as disabled or elderly dependents may be left adrift as a result of the death - particularly a sudden death. The family - especially if they live far away - needs to consider this possibility - especially in situations where the deceased left a dependent at home who may not be otherwise known to health care personnel or even to neighbours.

The survivors should also determine if there are any outstanding matters that require immediate attention. Sometimes there is real urgency to get the rent or taxes paid, a house or car paid off, or animals taken care of.

Finally, in the entire hubbub, it is important to take some time to simply remember the person who just died, to be in touch with loved ones, to pray, and to reflect.

4 – 3.6 Decisions about Autopsies

If the death is sudden or unexpected, or at home, the medical examiner must be notified in order to determine whether an autopsy is required or not.

Family members have very little authority to stop public officials who want an autopsy (since the concern is usually one of public safety).

If an autopsy is ordered, it is important to know that it can often take two months or more to get the results. A preliminary set of findings is available shortly after the body leaves the morgue, but much turns on making microscopic examination of various tissues, and that can take weeks, even months. If family members want to have the results, they need to let the doctor or pathologist involved, know this. Sometimes, the best way to obtain the results is to set up a meeting specifically for this purpose.

But keep in mind, that even when the results are produced with a great deal of sensitivity, they can be a little cold and jarring. Considering this it is a good idea to bring along a trusted friend or counselor.

If the doctor or nurse says there is no need to notify the medical examiner, or if the medical examiner declines to do an autopsy, the next of kin may still wish to have an autopsy done. Autopsies help answer questions about what really happened. They also keep doctors and other caregivers on their toes since autopsies can turn up shortcomings that would otherwise have been unknown.

If the person died in a hospital, an autopsy is usually free. If the person died in a nursing home or at home, the situation is more complex. Sometimes the doctor can arrange for a free autopsy, but sometimes there is a fee - that the family must pay - and that can run into the thousands of dollars. The situation is complicated enough to warrant having considered it in advance whenever possible - especially if death is to take place at home.

The body after an autopsy still looks normal and can be shown in an open casket if that is the family's wish.

4 – 3.7 Death with Dignity

When faced with death, different people react in different ways. Most people hope for a "good death," however they may define it. A variety of reference materials are available to help.

If an elder is faced with making decisions about end-of-life care for themselves or someone they love, an excellent place to start is with the full-text extracts from the Handbook for Mortals, a caring and authoritative guide written by a team of experts in the field.

To ensure a "good death" and a dignified death, it is also important for the dying person to express his or her preferences about health care at the end of life. This can be done using formal legal documents.

4 – 3.8 Living Will/Advance Directive

Although covered elsewhere, a brief overview of living wills/advance directives is in order. These documents express the wishes and desires of a patient when death is imminent or when further treatment would be of no real benefit. Typically, advance directives may include statements to the effect that, in the event of a coma or impending death, no unusual means are to be used to resuscitate or prolong life.

These directives may be as specific as to specifically indicate which life support equipment is not to be used and that nourishment and liquids are to be withheld. There may also be cases when the living will direct the doctors to use all available means to prolong life, even if the ill person will never regain consciousness or will be permanently impaired as a result of the treatment.

Provincial legislation governs the making of living wills and advance directives in those jurisdictions that have implemented applicable legislation. Where there is no applicable legislation, provincial legislation dictates whether living wills and advance directives are permissible. In jurisdictions that have not legislated advance directives or living wills, a mentally capable person can express their wishes in writing.

Living wills or advance directives must be tailored to the elder’s specific situation and location, as laws vary around the world. They should also be designed to cover any issue that the elder considers important. A very common concern of this nature revolves around tube feeding and the related issues of palliative nutrition and hydration. As well the difficult decisions that need to be made concerning the withdrawal of life-sustaining treatments should be addressed.

Another important issue concerns whether the dying elder wants to choose home or hospice care as an alternative to a hospital environment. Regardless of whether death is to take place at home or in a hospital, it is important to demand top-quality palliative care and pain management.

A person making a living will should consult their doctor to understand the issues involved. Living wills should be prepared by a lawyer who is competent in such matters and familiar with the laws of the applicable jurisdiction. Copies of the living will should be provided to the patient's primary doctor, family members and other trusted professionals.

4 – 3.9 Powers of Attorney for Personal Care/Health Care Proxy

Power of attorney for personal care and health care proxies will be covered in more detail in a later chapter. These documents address much broader health care issues than what is covered by living wills and advance directives.

Powers of attorney for personal care and Health care proxies may be limited or unlimited and grant someone the authority to make medical decisions on behalf of the principal and to respond to changing health and medical needs as they occur. In situations where an advance directive regarding health care decisions has not been made or a guardian has not been appointed by the court, family members, depending on their relationship to the elder, may be authorized by legislation to act on his behalf.

If the elder has private health insurance, he should to give information regarding the insurer as well as all relevant identification numbers to next of kin or substitute health care decision-maker. Even if the elder is in a nursing home, this information will be required for extended benefits, such as a semi-private or private room if he is unexpectedly hospitalized.

4 – 3.10 Choosing a Decision Maker

Persons chosen as substitute decision-makers (agents) should be carefully considered for their trustworthiness, reliability, compatibility with other interested parties. It is also important to consider their willingness to act and ability to deal with professional accountants, lawyers and health care providers to make appropriate decisions in the elder's best interests.

An alternate agent should also be considered in case a person's first choice cannot act. At times, multiple agents may also be desirable. Provincial legislation will generally specify how the agents are to act, unless otherwise stated by the elder in the document. If no enduring power of attorney exists and a person is no longer competent to execute such a document, a friend or family member may choose to apply to court to become guardian or similar representative of the elder's property. The Public Trustee, Public Guardian and Trustee or similar public office, depending on the jurisdiction, may also apply to court to manage a person's affairs. In either of these cases, there is no guarantee that the guardian appointed by the court would be the elder's choice. To avoid this outcome, everyone should have a power of attorney.

4 – 3.11 An End-Of-Life Checklist

Professionals, who work with elders, usually recommend that a document be prepared - prior to death - which includes all the important information on the person who **is** nearing death.

In addition to indicating the location of the will, their wishes concerning funeral arrangements - this document should also include:

- ❖ A list of all family members including full names and contact information
- ❖ A list of all prior marriages including any children from each marriage
- ❖ A list of all bank accounts and insurance policies complete with any reference numbers
- ❖ A list of all assets, business interests, and credit cards, etc.
- ❖ Information on where the safety deposit box and keys are located

4 – 3.12 Estates and Wills

Although estates and wills are covered in some detail elsewhere, a few brief matters need to be covered here. When planning for a death it is a good idea to determine if an up-to-date will exists - and if it does not, it is a good idea to have one prepared.

A will is very helpful in settling an estate, and it is astonishing how much of an estate even people of modest means will have (a car, a few stocks, a savings account, a debt owed, or a debt to pay, and so on).

If there is no will, generally close family will have to go to their county courthouse and get instruction on how to have someone named as "executor." That person will have to report to the court as to what the person owned and how it was dispersed. If wealth is passing to a spouse, tax laws are lenient. If wealth is passing to others, however, taxes are often substantial. If the estate is worth much, the family should seek the advice of a lawyer.

Working through these issues before a loved one dies can be calming and reassuring and is usually helpful to the family.

4 – 3.13 Other Issues

There are also a variety of other issues that must be addressed at or before a death. Practical issues like eldercare, estate planning, funeral planning and memorial arrangements.

Getting one's affairs in order also includes working through deep emotions with friends and loved ones, including dealing with grief and bereavement.

There are also spiritual matters to attend to. Many faith traditions place emphasis on the importance of conscious preparation for death as a way of showing respect for and acceptance of life's final adventure. Contact with death often gives society an opportunity to become more aware of these spiritual realities.

Remember that death is not the opposite of life—it is the opposite of birth.

4 – 4 END OF LIFE HEALTH CARE

On the most fundamental of levels, there are two competing views with respect to end of life health care. Some believe that life must be preserved and extended for as long as is humanly possible - while others believe that "quality of life" or lack thereof, is a key consideration in deciding whether to extend life with "heroic" measures.

4 – 4.1 Quantity versus Quality of Life

Questions concerning the use of life-sustaining medical care frequently revolve around judgments about what constitutes acceptable "quality of life" and - by the same token - acceptable "quality of death."

Evaluations of "quality" are subjective and personal. What is an acceptable quality of life to one person may be a fate "worse than death" to another? Similarly, life-sustaining treatment that some would gladly endure, others would reject as "too burdensome" or simply "undignified."

On the one side of the argument we have people who believe that life, whatever the quality, is sacrosanct.

To them, the possibility of sustaining life justifies, or even dictates, the use of all potentially effective means. In contrast, many other people believe that the present and expected future quality of life is a valid, even essential, consideration in decisions about whether to apply life-sustaining treatments. These fundamental disagreements about quality vs. quantity are frequently expressed in terms of treatments that "prolong life" versus treatments that "prolong dying."

4 – 4.2 End-of-Life Care

Medical technology continues to seek cures for practically every health condition known to humankind. However, sometimes there is no cure for a fatal disorder. Decades ago, the patient may have been left to wither away, sometimes in extreme pain.

Today, however, many medical centres have palliative care programs designed to care for patients as they near the end of their life.

As patients move away from life-prolonging goals, they should focus on short-term goals oriented to comfort. These might include alleviating dry mouth, improving pain control, avoiding further hospitalizations, or returning home. Advancing these goals without adding unnecessary burden is the focus of palliative care.

The patient should be the person in control - deciding which aspects of care are most meaningful to him or her. With an inpatient hospital setting, the patient should be given the ability to question any medical tests or routines assumed to be ordinary care, whether it is chemotherapy, blood tests, etc.

Ordinary hospital measures, such as checking vital signs, may be unwanted by a terminally ill patient. Since making these decisions may be difficult and since there may be some disagreement between the patient, family and the medical team - it is a good idea to involve a palliative care consultant who can help everyone to sort through the issues.

The care provided should also address the numerous psychological and spiritual issues that impact a terminally ill patient. Fear or denial of impending death, concerns about his or her family or finances, as well the search for meaning, are common issues that the terminally ill must deal with. Family members and the medical team need to understand the intensity of these issues. A palliative care consultant can provide or arrange counseling for the patient and/or family. Sometimes discussing prognosis information or encouraging short-term goal setting (e.g., going home) is helpful.

While many terminally ill patients have a family and friends to provide the necessary physical, spiritual, and emotional support, others do not. Often a patient is concerned about being a burden to others. A palliative care consultant can help patients identify support resources beyond family and friends to include people from their work, church, neighbourhood, and even hospital volunteers.

The most important piece of information to help determine appropriate treatment, set short-term goals, and arrange for discharge planning, is a patient's prognosis. The most important question is simply, "How long does the dying person have?" This information is vital to helping patients and their families prepare themselves psychologically for death - even though many health care professionals are quite reluctant to provide an estimate.

Knowing roughly when death might occur allows health care providers to mobilize community support services, particularly home hospice care. But, as noted earlier, patients should realize that predictions are far from certain. A massive, fatal stroke can happen to virtually anyone at any time, including those who are already terminally ill. Predicting a prognosis beyond three to six months becomes increasingly difficult to do with any certainty, particularly if there are several health factors involved.

Thanks to a large mass of existing data, establishing an end-of-life prognosis for cancer is easier than for other conditions, such as end-state heart disease, lung disease, or dementia. It should also be noted, that in any attempt to predict when death will occur, experienced physicians make more accurate predictions than inexperienced ones.

For hospitalized patients, there are several discharge options to consider, and since physicians, nurses, and hospital discharge planners may not have all the answers, a palliative care consultant may be needed. Options include staying in the hospital, transferring to a long-term care facility or nursing home, or going home. If hospice care is recommended, it can be provided anywhere.

Most patients want to be at home but may be concerned about burdening their family. Family members may not have the physical and emotional ability to provide effective support for an extended period, around-the-clock, if needed. They may not possess the technical skills necessary, either, depending on the prescribed treatment.

Sometimes a symptom control plan can be developed that makes home care easier, such as the use of oral medications, rather than injections.

A patient who is approaching the end of his or her life has many decisions to make. Along with family members, a medical team that includes a palliative care specialist can be of assistance during this difficult time. The key issues are to control symptoms, provide emotional support, and deal with any outstanding financial issues.

4 – 4.3 Federal Government Role in End-Of-Life Care

End-of-life care, like all other health care is largely the responsibility of the provincial and territorial governments. The Federal Government, however, does play a part in end-of-life care through the transfer of funds and the establishment of broad guidelines. There are, in short, some jurisdictional overlaps involved in the delivery of end-of-life care. Fortunately, there is a consensus that all Canadians are entitled to continuing quality health care up to the moment of death.

In June of 2001, the Federal Government established the Secretariat on Palliative and End-of-Life Care at Health Canada. The Secretariat was directed to facilitate collaboration and coordination of effort with other federal government departments and agencies, representatives of national associations, professional associations, universities, researchers, the community, and provincial and territorial governments.

4 – 5 HOSPICE / PALLIATIVE CARE

"Palliative care" is care aimed at alleviating suffering—physical, emotional, psychosocial, or spiritual—rather than curing. It is concerned with the comfort of the suffering individual.

In Canada, "hospice" and "palliative care" mean the same thing in most provinces. In other jurisdictions, the term "hospice" is used to describe a residential facility.

The Canadian Hospice Palliative Care Association has developed a definition of palliative care that reads:

“Hospice palliative care is aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved. Palliative care is a special kind of health care for individuals and families who are living with a life-threatening illness that is usually at an advanced stage. The goal of palliative care is comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family. A 'family' is whoever the person says his or her family is. It may include relatives, partners and friends.

An important objective of palliative care is relief of pain and other symptoms. Palliative care is planned to meet not only physical needs but also the psychological, social, cultural, emotional and spiritual needs of each person and family. Palliative care may be the focus of care when a cure for the illness is no longer possible. Palliative care services help people in later life who are ill to live out their remaining time in comfort and dignity.

Palliative care services are helpful not only when a person is approaching death but also at earlier stages in the illness. Palliative care may be combined with treatments aimed at reducing or curing the illness, such as chemotherapy. Families benefit not just from support when their loved one is dying - but also after his or her death.”

The World Health Organization defines palliative medicine as “the active total care of patients whose disease is not responsive to curative treatment.”

End-of-life care is designed to treat the whole person and is based on a meeting or consultation with the patient and his or her family. A palliative care consultation should be requested whenever a patient and his or her family are faced with a terminal illness.

The essential components of this consultation are assessing and managing physical symptoms, helping patients identify personal goals for end-of-life care, assessing and managing psychological and spiritual needs, assessing the patient's support system, and communicating the estimated prognosis; and assessing any discharge planning issues.

Understanding the patient's discomfort is the first step in a palliative care assessment. Pain is not the only end-of-life symptom. Other symptoms include dry mouth, nausea, water retention and swelling, lack of appetite and shortness of breath. The degree to which these symptoms affect daily living varies widely between patients. In addition to medication and other interventions, it helps patients if they know what is causing their symptoms. Ultimately, they may have to decide if they wish more diagnostic evaluation and more aggressive treatment, which can cause discomfort. "Over treatment" is, unfortunately, a common problem with end-of-life care.

4 – 5.1 Hospice Palliative Care in Canada

According to the Canadian Hospice Palliative Care Association's most recent Fact Sheet, less than a third of Canadians who died had access to or received hospice palliative and end-of-life care services. Even fewer received grief and bereavement services.

When asked, most people have indicated that they would prefer to die at home in the presence of loved ones, yet close to 70% of Canadian deaths occur in a hospital. Canadians living in remote and rural areas, or those living with disabilities, are particularly disadvantaged. Both receive severely limited access to formal hospice palliative care services.

The leading causes of death in Canada are neoplasms (tumours or cancers) (about 25%), diseases of the circulatory system (about 22%) and diseases of the respiratory system (about 8%).

Hospice palliative care programs and services are beneficial for all these groups, which represent over half of all Canadian deaths. Part of the problem is cost. Canadian families frequently shoulder 25% of the total cost of home-based palliative care services. Another issue is access to resources. Ninety five percent of Canadians have indicated that they would need outside help in order to die at home surrounded by loved ones.

On a more positive note, the Economist's Intelligence Unit ranks Canada as ninth in an international 'Quality of Death' index. The 'Quality of Death' index measures current hospice and palliative care environments across 40 countries in terms of the quality and availability of end-of-life care. Although Canada scored within the top ten countries examined, we are still unable to provide valuable hospice palliative care services to over 70% of those dying within Canada.

Palliative care is provided in hospitals, residential hospices and nursing homes, but it is not sufficiently funded outside of these institutions. Funding for in home palliative care is, in fact, totally inadequate. The National Leadership Roundtable on Health Reform reported that funding for health care in Canada does not reflect the necessary realities of the services needed, and that spending on physicians and hospital services leaves many other services (including end-of-life care) "out in the cold."

The cost of being able to stay at home when terminally ill is considerable, and the patient or the family usually must find this money.

Some health services associations and companies in Canada provide in-home nursing care (using home support workers), so that the expenses of terminal care are partially born by this system.

In addition, the 650-odd voluntary hospice organizations in Canada supply some support. Unfortunately, they are only able to ensure that a very small percentage of dying Canadians receives hospice support.

The largest volunteer hospice organization in Canada is the Canadian Hospice Palliative Care Association. It has grown from 8 to 180-member agencies since 1989, and now has over 14,000 active volunteers.

The Vanderhoof Hospice Society of B.C. represents a typical Canadian hospice organization. There is a board of directors and a part-time paid coordinator.

The coordinator is responsible for organizing the volunteers, who work in different areas including fundraising, office work, education, and, chiefly, with dying persons and their families and loved ones. After a referral to the hospice, the coordinator arranges to visit. A volunteer attends as well, and subsequently spends considerable time with the patient. This can involve reading, playing games, going on excursions, or simply sitting beside the patient and "being there."

To date Canada has 88 residential hospices. Hospice Wellington in Guelph is one of them. In 2018-2019 served 294 residential patients and their families. Services such as massage, pet therapy, therapeutic touch are offered free of charge to patients and their families. In addition art therapy, bereavement groups including a bereavement walking group are offered to client families.

Canadian hospice volunteers are not responsible for any personal care of the patient. The staff in hospital, in residential hospice or care-aids in long term care facilities are responsible for personal care.

In general, the overall knowledge of hospice care in Canada is very poor. According to a recent survey, only 50% of Canadians had ever heard of hospice care, and only a third of these could describe it adequately.

Dr. Harvey Chocinow expresses it thus: " Unfortunately, in end of life care, we do not have a vocal constituency: the dead are no longer here to speak, the dying often cannot speak and the bereaved are often too overcome by their loss to speak."

To raise awareness the Canadian Hospice Palliative Care Association hosts ***National Hospice Palliative Care Week*** during the first week of May each year. Other programs offered include Advance care Planning and Caregiving and more.

Hospice care tends to focus its attention in four areas: pain management, symptom management, social, psychological, emotional, and spiritual support, and caregiver support.

4 – 5.2 Pain Management

People living with a life-threatening illness may experience pain.

Health care providers work with elders and their families to identify the source of the pain and ways to relieve it. Pain may be managed with drugs or by other means such as massage therapy and relaxation techniques.

4 – 5.3 Symptom Management

Often people must deal with a variety of other symptoms. These can include loss of appetite, nausea, weakness, breathing difficulty, bowel and bladder problems, and confusion. Palliative care can help relieve these distressing symptoms.

4 – 5.4 Social, Psychological, Emotional and Spiritual Support

Palliative care focuses on the person by offering a wide range of support services. It also offers bereavement support and can help the family work through emotions and grief regarding the illness and death of a loved one.

4 – 5.5 Caregiver Support

Elders may be concerned about whether they will be able to cope, especially when the person they are caring for is living at home.

Palliative care services that help the family cope include:

- Advice and assistance from health care providers such as nurses and doctors who are skilled in providing palliative care
- Instruction on how to care for the person (how to give medication, prevent skin problems, recognize signs, call for help, etc.)
- Home support services that provide assistance with household tasks such as meal preparation, shopping, and transportation
- Relief for the caregiver. Sometimes a volunteer stays with the person so the family caregiver can go out. In other situations, the person who is ill may go to a day program, or enter a hospital or a long-term care facility for a short period

4 – 5.6 The Palliative Care Team

The palliative care team is determined by the needs of the ill person and his/her family. It often includes nurses and a physician with specialized palliative care skills, the family physician, a social worker, a spiritual counselor and a pharmacist.

Other health professionals such as nutritionists, physiotherapists, occupational therapists, and home support workers may be added to the team, as needed. As noted above, volunteers can also play an important role in palliative care, providing support services such as companionship, relief for the caregiver and transportation.

4 – 5.7 Where Do People Receive Palliative Care?

Palliative care is offered in a variety of places—at home, in long-term facilities, in hospitals, and occasionally in hospices. Individuals and their families need to know about the choices they have.

At Home

Palliative care is often provided in people's homes through home care programs. These programs offer professional nursing care and a variety of home support services.

Other services may be available in some communities to help people to remain at home. These can include volunteer services, day programs offered for the ill family member in a variety of places in the community, pain and symptom management teams, and 24-hour response teams that help with urgent needs on a short-term basis.

Being at home allows people to remain close to their families and live as normally as possible. Some people feel that when they are at home, they have more freedom to make choices about their care. There may be situations where people cannot stay at home or choose not to remain at home to receive palliative care. In these situations, other options are available.

In Long-Term Care Facilities

Long-term care facilities such as nursing homes also offer palliative care services. It is sometimes necessary for residents who need more specialized palliative care services to enter a hospital - since hospitals are more likely to have specialized palliative care units.

In Hospitals

Some hospitals have specialized palliative care units. Others set aside a certain number of beds in different hospital units for people needing palliative care.

Hospitals that have a palliative care team, composed of health professionals who have specialized in this type of care, can help other staff provide palliative care in the unit where the ill person is located.

In Hospices

In Canada, there are only 88 residential hospices—separate buildings or apartments in the community where palliative care is provided in a home-like setting. Some people move into such hospices to receive palliative care on a 24-hour basis.

4 – 5.8 Who Pays for Palliative Care?

Palliative care is paid for in different ways across the country.

It is important that people requiring palliative care and their families find out as soon as possible who pays for what and what additional financial assistance may be available.

Who pays often depends on whether care is being provided at home or in the hospital?

Palliative care costs at home may be covered by the provincial health plan as part of a home care program. These plans do not always include the cost of drugs and equipment used at home, however. Some allow only a certain number of paid hours of professional and home support services. After the hours are used up, people need to look for other ways to pay. People may use private insurance or their own money to pay for palliative care services at home. Some may receive assistance from social agencies, service clubs, local cancer societies, and other similar organizations.

Palliative care provided in a hospital is usually paid for by provincial health plans. These plans usually cover most care including drugs, medical supplies, and equipment while the person is in the hospital. In long-term care facilities, residents are usually required to pay for some of their care. Costs vary among facilities.

In some cases residential hospice depends on a mix of government, grants and memorial donations. Other funds come from hard working fundraising.

There is usually no charge for bereavement support. It is often provided as part of palliative care services of hospitals or by non-profit or volunteer organizations in the community.

In order to obtain information about palliative care services, an elder or his or her family can contact their family doctor or specialist, a home care nurse, a hospital social worker, a spiritual counselor, or a national, provincial or local palliative care association. Also contact any local elders' groups, the Cancer Society or other organizations concerned with specific diseases (e.g., heart disease, Alzheimer Disease, AIDS).

A very good and reliable source for information about palliative care in Canada is available through the Canadian Hospice Palliative Care Association (CHPCA).

4 – 5.9 Rural Palliative Care

Just as births can take place in either a hospital, a birthing centre, or at home, so too can palliative care be given anywhere.

"When it comes to rural palliative care, a large part of the comfort component comes from staying in the community, surrounded by familiar faces," says Michael MacLean, director of Age Wise Inc., a consulting firm that researches the health and social issues of aging.

Given the long distances, the impact of adverse weather, and scarcity of health care resources in the rural environment, supporting a patient and his or her family within the community can be quite difficult. The fact that palliative care is usually tailored to and dependent on a patient's individual needs and wishes merely further complicates matters.

4 – 5.10 Rural Programs

Palliative care is a relative newcomer to formal health care, and rural palliative care is even newer. This newness and the fact that it is unique to each patient, institution, and community means that there is not yet a common guiding philosophy or definition of rural palliative care. Several rural palliative care programs exist across Canada, some in small communities, others as outreach programs associated with programs in larger urban centres. A primary concern of these programs is keeping the patient in the community for as long as possible.

Since the number of palliative cases in a rural community at any one time is small, the expertise of the health care providers in managing patients' needs is often limited. Programs, therefore, often establish and maintain contact with a knowledge base outside the rural community.

At the same time, the local community has strengths and informal networks of resources to contribute to any situation. The rural palliative care programs tend to be more flexible than their urban counterparts in meeting the individual needs of patients, using these networks of assistance whenever necessary.

4 – 5.11 Rural Services

The pain management and comfort needs of every patient are only partially medical. “We provide nursing care, homemaking services, occupational therapy, speech therapy and physiotherapy, nutrition assistance, and counseling, as well as pain medication administration in our palliative care," reports Karen Roosen, Director of Client Services for the Community Care Access Centre in rural Renfrew County, Ontario.

"Services available in different parts of the province and the country vary," she adds. In Renfrew County, a case manager co-ordinates the delivery of services to the patient and works with the family and medical staff to remain aware of the needs of the patient and family caregiver.

Unlike in the urban setting, where so many services are available that it can be difficult to know them all, rural palliative care resources are scarcer. There is an unexpected benefit to this, comments MacLean. “You don't have to play a guessing game to find programs. Everyone knows what's available and will help as much as they can.”

It is also more common for other community agencies and service clubs to get involved as needed, providing transportation or funding, she adds.

4 – 5.12 Advice to Caregivers

A family member primarily administers rural palliative care with support from community and hospital services. Faced with the responsibility of caring for a terminally ill family member - often in addition to the demanding work of running a farm can be trying.

To manage, “they work harder,” says Michael MacLean. “They can't neglect the farm work, and they can't neglect the patient.” This can lead to stress, exhaustion, burnout, and physical illness in these caregivers. Caregivers need to take care of themselves - not just the dying family member. They should not shy away from asking for help when they are overwhelmed.

Here are some ideas to assist the caregiver:

- Take time for yourself, out of the home if necessary
- Make sure you get enough sleep and proper nutrition
- Find out what resources and services are available and use them

Caregivers who are under significant stress should use respite care programs if they are available. These programs typically offer alternate caregivers, short-term nursing home stays, or day programs giving the primary caregiver some rest. The caregiver should limit his or her other activities and responsibilities as much as possible. They are doing a very difficult job and should not condemn themselves for occasional feelings of frustration, resentment or anger.

4 – 6 LIFE AND DEATH DECISIONS FOR ELDERS

During periods of personal crisis, the dying person, family members, or significant others will often have to meet with healthcare professionals to make life or death decisions. In the past, physicians typically made decisions of this nature. They decided - often behind closed doors - whether to withhold life-sustaining technologies.

It was believed that in doing so, they were protecting their patients and family members from what might be a highly upsetting decision.

However, recent legal developments pertaining to living wills and the Durable Power of Attorney for Healthcare support the rights of incapable adults, or a surrogate, to be informed about medical conditions, and to participate in decisions about medical care.

A living will is allowing a person to put in writing their preferences regarding terminal illness and the use of life-sustaining technologies.

And when a person is named as an agent, using the Durable Power of Attorney for

Healthcare document, that person may be asked to make life or death decisions on behalf of a loved one when he or she no longer can. For anyone who is given this authority, it makes sense to have some knowledge with respect to life-sustaining technologies, and some understanding of one's ethical and moral obligations.

At any one time, many thousands of elders are receiving life-sustaining interventions. Most cases go unnoticed except by the patients, family members, and others directly involved in making and living with difficult treatment decisions. However, a few of these cases gain notoriety and public attention as it becomes apparent either that treatment was unwanted or futile or, conversely, that some new medical breakthrough or personal triumph over adversity has occurred.

Technologies that support or replace the functioning of a vital organ are capable of saving and sustaining life and, sometimes, capable of restoring health and independence. However, an individual's response to treatment can seldom be predicted with certainty; thus, it is never clear that a "life-sustaining" technology will sustain the life of a patient or, if it does, for how long. The quality of the life that is sustained may be even harder to predict.

An important factor that further complicates matters is that many patients with life-threatening conditions are not able to understand their treatment options or to express preferences regarding them. In addition, patients and other interested parties may evaluate differently the benefits and burdens associated with treatment versus no treatment and with one treatment versus another.

The dramatic advances in life-sustaining medical technologies during the past three decades have been accompanied by rapid expansion in their availability and use. As equipment and procedures have been refined and experience accumulated, the necessary personnel, facilities, and reimbursement have expanded, and the clinical criteria guiding use of these technologies have been broadened. The types of patients who become candidates for life-sustaining treatments have changed and their numbers have increased sharply.

Many of these patients are elderly. As the population ages, as once "extraordinary" measures become commonplace, and as ever more powerful technologies emerge, it becomes increasingly important to understand the problems associated with the use of these technologies.

At such times, patients or their representatives may request "no heroics" be provided or, conversely, that "everything possible" is done. These broad directives are open to a variety of interpretations by healthcare providers and patients - and families sometimes fail to consider the implications of their request. For example, resuscitation can be the starting point of prolonged dependence on other technologies such as mechanical ventilation.

The patient or family members who request "no heroics" may feel quite differently about a simple procedure like an external cardiac massage than how they feel about a more invasive technique like open-chest massage, defibrillation, and pacing. Yet, there is no way to distinguish between life-sustaining technologies when wishes are expressed in global terms.

Advances in medical technologies are providing considerable ability to alter the timing and circumstances of death. However, questions of this life-sustaining medical care now frequently revolve around judgments about what constitutes acceptable "quality of life" (and, implicitly at least, "quality of death"). Judgments of "quality" are subjective and personal. The problem becomes even more complicated when you consider the legal, moral, ethical, and financial issues.

"Withholding of life-sustaining treatment" is not starting treatment that has the potential to sustain the life of a patient.

In the past, a decision to use or withhold a life-sustaining treatment for an individual was based on consideration of the person's physical condition, legal and ethical constraints, and, in some cases, the wishes of the patient and family. Everyone in Canada, including elders, is largely insulated from cost considerations about life-sustaining treatments.

For those who sign living wills stating their wishes regarding life-sustaining treatment, and for those who may carry the burden of deciding for another, an explanation of these technologies will be provided on the following pages.

4 – 6.1 Life-Sustaining Technologies

Life-sustaining technologies are drugs, medical devices, or procedures that can keep an individual alive who would otherwise die within a foreseeable, but usually uncertain, period. While these technologies share some common ethical, legal, and healthcare delivery problems, each has unique characteristics that either raise special questions or suggest possible solutions.

Although there are several technologies used to treat or manage life-threatening conditions, five important ones are:

1. Mechanical ventilation

2. Resuscitation

3. Renal dialysis

4. Nutritional Support and Hydration

5. Antibiotics

4 – 6.2 Life-Sustaining Decisions & the Caregivers

Decisions about whether to institute life-sustaining treatments would be relatively easy if it were known in advance whether the patient would survive, for how long, and in what condition. However, variations in patients' physiological and psychological adjustment, and in the quality of care they receive, make highly uncertain the outcome of any treatment for any given patient. The prognosis is especially difficult when the patient is elderly. The inability to identify patients who will benefit from treatment arises because, contrary to popular belief, life-sustaining technologies are frequently ineffective. For acutely ill patients, aggressive treatment is associated with high death rates and serious complications. At best, one-third to one-half of all in-hospital resuscitation attempts succeed; and only one-half of the patients who are successfully resuscitated survive long enough to be discharged from the hospital. In acute episodes of respiratory failure, adults treated with mechanical ventilation have about a 50% chance of surviving; for acute kidney failure, only 20% of persons over age 70 survive. Patients receiving antibiotic therapy or nutritional support have a relatively high, but not necessarily predictable, chance of survival.

Many people regard controlling pain and suffering a reasonable alternative to aggressive life-sustaining medical treatment, even at the risk of hastening death.

In addition, there are legal and ethical uncertainties regarding when or how it may be appropriate to limit treatment.

Decision-making problems are made still more complex by the fact that, in most cases, there is not one decision to be made (e.g., whether to start dialysis), but rather a series of decisions (e.g., whether to hospitalize, to do a diagnostic test, to put the patient in ICU, to continue treatment, etc.).

Moreover, separate from the question about what the decision should be are serious questions about how the decision should be reached.

If, for example, the patient disagrees with medical advice, what should be done? If the patient is not mentally capable, who shall be the surrogate if one is not named?

4 – 6.3 Issues for Physicians

Caring for critically ill, terminally ill, or severely debilitated patients who may be treated with life-sustaining technologies is demanding and highly stressful for health care providers. In addition to the emotional load of dealing with very ill patients and grieving relatives, health professionals are constantly reminded of their own mortality and their own fallibility. Emotional detachment from patients, avoidance of patients' families, and overuse of technologies are not uncommon responses.

Almost no training is available now to help professional caregivers deal with their own feelings of loss, grief, and self-doubt. They are left on their own to develop coping strategies, which at times are detrimental to their own well-being or may affect their professional performance.

Physicians' responses to patients' deaths may bring emotional and behavioural symptoms that can lead to such negative behaviours as minimizing contact with the patient or family, blaming others, and turning to alcohol or drugs. The ability of caregivers to resolve their personal feelings requires the kind of understanding that death education may help to provide.

4 – 6.4 Physicians Duty to Treat

Usually, the terminally ill are also the elderly. Societal values that emphasize youth and work success, coupled with increased health problems and often frailty in the elderly, tend to reduce the respect in which the elderly are held. This can occur without conscious intent. Ageism, like racism, is morally wrong and cannot be part of the physician-patient relationship. Legally, the age of the elderly patient is irrelevant.

The elderly, confused patient with a terminal lung cancer has the same right to diagnosis and treatment as any other patient. When the physician is very busy, that can be forgotten.

Confusion that may be caused by cancer can also be caused, for example, by a drug reaction, or hypoxia caused by pneumonia. The patient has the right to a diagnosis and, if consented to, the physician has a duty to treat.

The Code of Ethics of the Canadian Medical Association puts it very succinctly:

“In providing medical service do not discriminate against any patient on such grounds as age ... physical or mental disability ...” (Rule #17)

4 – 6.5 Canadian CPR Directives

The 21st century dawns with two major realities colliding together in the health care environment. Medical technology is advancing at a rate far ahead of society’s ability to learn how to be good stewards of it. Sometimes this technology can meaningfully prolong life, but sometimes it also has the opposite effect of prolonging the dying process unnecessarily. At the same time, patients increasingly are faced with health care decision-making that is guided both by a desire to minimize suffering in the face of terminal illness, and an attempt to somehow wade through the myriad of issues related to the use of technology. Without contrary indications, hospital medical staff is required by law, and doctors by the Hippocratic Oath, to provide the full range of available treatment and life-sustaining technology to those admitted to the hospital.

If an elder does not want to be resuscitated, it is important that he prepare an Allow Natural Death (AND) or a Do Not Resuscitate (DNR) order. A document of this nature instructs medical personnel not to perform lifesaving cardiopulmonary resuscitation (CPR) or other procedures to restart the heart or breathing once they have ceased.

The physician can write an order on a patient's health record about a living will or advance directive or if, in the physician's judgment, resuscitating the patient would be futile or not beneficial.

Elders should be certain that the physician and the person named as their health care proxy are aware of an AND or a DNR order if they have one. In this situation, a physician should communicate with the patient, family and hospice staff to establish a treatment plan.

Surprisingly, few people who end up in the hospital bother to inform their doctors in writing about whether they wish to be revived, an international study has found.

Most critically ill patients undergo cardiopulmonary resuscitation (CPR) by default unless patients or their families explicitly state not to resuscitate.

When researchers looked at patients at the end of their first day in intensive care, they found nearly 90% had not signed resuscitation orders. Doctors were often forced, as a result, to take heroic measures to try to save their lives. An investigation was done in 2001 at Hamilton's St. Joseph Hospital to examine CPR directives - or lack thereof. Remember that in the absence of documentation of patient preferences, it is assumed that patients would want to be resuscitated.

Over 2,900 adult ICU patients from four countries, Canada, USA, Australia, and Sweden, were recruited for the study. Investigators recorded whether, when, and who gave the patients' CPR orders. The results were as follows:

- 318 patients, or 11%, had an explicit resuscitation order established within 24 hours of ICU admission—half of those had do-not-resuscitate (DNR) orders
- Just under half (46%) were made by ICU residents or junior doctors
- Age also mattered. Patients aged 50–64 were three times more likely to have a DNR. Patients aged 65–74 were four times more likely, and those aged over 75 were around nine times more likely to have a DNR than younger patients
- It was more common for "do not resuscitate" orders to be given in the first 24 hours of ICU admission, at night and on weekends

The fact that many directives were initiated by junior doctors is disturbing. These physicians likely had little previous knowledge of the patient or their social environment and they were also under the pressure that accompanies clinical care of a large group of critically ill patients during off-hours when there are no family members present.

Advance directives are not for everyone, but the findings suggest doctors and hospitals could do more to find out what their patients want. This is a situation where people could become involved and could be communicating their preferences.

4 – 6.6 The Health Care Directives Act

An AND or DNR Order, a decision to forego CPR, does not limit in any way the implementation of any other medical appropriate treatments or procedures. The patient's physician writes AND or DNR Orders on a patient's medical chart. An order to reverse an AND or DNR Order must also be written on the patient's medical chart by the patient's physician.

The decision to resuscitate must comply with the accepted standard of the medical profession. The physician must determine and document the relevant criteria accepted by the profession for the decision not to implement or discontinue therapy. The responsibility to consider the family in issues relative to patient care becomes more relevant when the patient cannot contribute. In a situation involving withdrawal or non-provision of treatment, clear communication becomes very important, even though the issue of consent is not relevant.

4 – 6.7 Canadian Medical College Recommendations

All facilities are expected to have policies regarding AND and DNR and supportive treatment orders. Policy makers should determine how controversial concepts applied to CPR should be interpreted into the policy, considering the facility's mission, the values of the community it serves, and ethical and legal developments. All members of the medical staff should be familiar with the policy. The College recommends that if the person for whom resuscitation is being considered is deemed incompetent, decisions made on his or her behalf should be based on the following principles:

- The treatment decisions must be based on the wishes of the person if they are known
- When the person's wishes are not known, treatment decisions must be based on the person's best interests determined by the diagnosis/prognosis
- Discussions with the partners and close family members
- The person's known values and preferences
- Aspects of the person's culture/religion that would influence a treatment decision

It is important to note that although informed consent from the patient or patient surrogate should be clearly understood and communicated, it is not mandatory.

The expressed opinions of the patient, family, and other caregivers regarding DNR orders are to be considered; but this is only a recommendation and not a prerequisite established by the College.

4 – 7 CANADIAN RIGHT-TO-DIE ISSUES

The decision to end one's life when death is approaching anyway is sometimes called self-deliverance, rational suicide, physician-assisted suicide (PAS), or voluntary euthanasia. The "right to die has been the subject of controversial legal battles on an international scale.

The famous Sue Rodriguez case raised the issue legally, politically, ethically, and morally of whether an individual has the right to control how they die in the event of terminal illness and suffering.

4 – 7.1 Sue Rodriguez Case: Led the Way to MAID

Canadian, Sue Rodriguez, developed a serious, paralysing and fatal ALS diagnosis. Amyotrophic lateral sclerosis is sometimes called "Lou Gehrig's disease," named after the baseball star that died of it in 1941. It causes a slow deterioration of the nervous system while leaving the mind intact. It is incurable, and its cause remains a mystery.

As it progresses, it slowly takes away a patient's ability to walk, and then their ability to talk, and eventually their ability to breathe. Most patients eventually die by suffocating or choking. Rodriguez realized her own death would be grim: unable to speak, fed by tubes, and breathing on a respirator. She thought about the death that lay ahead and decided, no, she would rather not die that way.

4 – 7.2 The Decision to Die

Instead of waiting for a "natural" death, Rodriguez wanted a peaceful death, to die with dignity, on her own terms, in her own time. When the moment came, Rodriguez knew she would not have the ability or strength to end her own life. However, getting assistance in dying was illegal … and the law seemed unfair to Rodriguez.

Rodriguez's position was that a right to life includes the right to a dignified death under the circumstances.

Second, she argued it was cruel and unusual treatment for her to be unable to have someone to assist her under these circumstances.

4 - 7.3 The Court Challenge

Rodriguez took on the legal system to end her own life. She lobbied to change a section of the federal Criminal Code that made helping another person commit suicide punishable by 14 years in jail.

The final legal step was presenting her case to the Supreme Court of Canada, the highest court in the land. In 1993, Sue Rodriguez lost her legal fight.
The Supreme Court of Canada ruled against her by a 5-4 margin.

She stated that her efforts were to gain the right to die but also to leave a legacy, to achieve assistance in dying for those who too might be suffering as she did.

4 – 7.4 Rodriguez's Death And Legacy

Those who knew her well say Rodriguez lost her will to live when she was no longer able to hug her nine-year-old son in her arms.

She knew that soon she would not be able to communicate at all, to communicate her wish to die. She simply grew too tired to fight any longer.

On Saturday February 12, 1994, Rodriguez died. Her good friend, NDP MP Svend Robinson, admits he was there to witness her death and that there was a doctor present. Later, it was learned that she died of an overdose of two drugs. The doctor who helped Rodriguez to die was never identified and no charges were ever laid.

4 – 7.5 MAID (Medical Assistance in Dying)

Twenty years after Rodriguez's denial of a legal assisted death the law changed.

Finally, in a landmark decision the Supreme Court of Canada, in early 2015, ruled unanimously that all Canadians had the right to elect assisted suicide and they requested that Parliament develop appropriate legislation within 12 months. Under the law it is no longer a criminal offence in Canada for a physician to help someone end their life in certain circumstance.

On November 1, 2018, the published regulations to create a federal *monitoring* system came into force.

Medical assistance in dying is legal for:

- Those with a serious illness, disease, or disability.
- Those with a condition that cannot be reversed.
- The patient is in unbearable physical or mental suffering.
- Natural death is anticipated to be reasonably foreseeable.

4 - 7.6 Further Legislation

On October 5, 2020, the Minister of Justice and Attorney General of Canada introduced *An Act to amend the Criminal Code (medical assistance in dying)* in Parliament, which proposes changes to Canada's law on medical assistance in dying. Who can provide medical assistance in dying and who can help?

Those who can provide medical assistance in dying services are:

- Physicians
- Nurse Practitioners (in Provinces where this is allowed)

Those who can help provide medical assistance in dying include:

- Pharmacists
- Family members or other people that you ask for help
- Health care providers who help physicians or nurse practitioners

Note: Protecting the right of providers to act according to their beliefs and values

Not all health care providers will be comfortable with medical assistance in dying. The federal practice may not be consistent with a provider's beliefs and values. The federal legislation does force anyone to participate in MAID.

4 - 7.7 Steps in Obtaining Medical Assistance in Dying

1. Submit a written request.

2. Undergo medical assessments.

3. Wait a 10-day reflection period to receive the service.

Note: A request for MAID must be made of their own free will. The person must be able to make health care decisions for themselves and their request may be withdrawn at any time.

4 - 8 EUTHANASIA

The word euthanasia originated from the Greek language: "eu" means “good" and "Thanatos" means "death."

Medical Assistance in dying is now in effect in Canada and this term will be used more frequently than euthanasia or *active euthanasia.*

Other terms related to euthanasia may still be heard. Some of the different varieties of euthanasia are described below.

4 – 8.1 Passive Euthanasia

Passive euthanasia involves hastening the death of a person by altering some form of support and letting nature take its course.

For example:

- Removing life support equipment (e.g., Turning off a respirator)
- Stopping medical procedures, medications, etc.
- Stopping food and water and allowing the person to either dehydrate or starve to death
- Not delivering CPR (cardiopulmonary resuscitation) and allowing a person, whose heart has stopped, to die

Passive euthanasia involves the "withdrawal of life-sustaining treatment" - treatment that has the potential to sustain the life of a patient.

4 – 8.2 Involuntary and Non-Voluntary Euthanasia

The term involuntary euthanasia is used to describe the killing of a person who has not explicitly requested aid in dying.

Non-voluntary euthanasia involves euthanasia in situations where the patient is unable to either give or withhold consent. This is most often done to patients who are in a Persistent Vegetative State and will probably never recover consciousness.

4 – 9 CONCLUSION

If all variables remain the same, Canada can expect to have more than 750,000 people in need of palliative home care in just over 30 years.

With a rapidly ageing population and a rise in the number of individuals being diagnosed with advanced illnesses such as cancer, it is vital that all Canadians have access to programs, support and treatments that will provide them with comfort and dignity at end-of-life; however, the results of a new Progress Report show that at least two thirds of Canadians (63 percent) who are dying, do not have access to adequate hospice palliative care. Hospice Palliative Home Care in Canada: The report revealed that 13 jurisdictions across Canada have in fact made progress in improving access to palliative home care services (case management, nursing, personal care and pharmaceuticals) - but there is still much more work to be done.

There is a growing trend toward Canadians wanting to die at home, yet 60 percent of deaths in Canada occur in hospitals. One of the main reasons that people need to be hospitalized at the end-of-life is to gain access to the medications they need with no financial burden for their families. Almost all the responding jurisdictions provide

Most of us want to have a "good death." What many of us forget is that ensuring one requires both foresight and planning.

4-10 REFERENCES

Canada, Health Canada. Palliative Care: Info Sheet for Seniors, Division of Aging and Seniors; Canada, National Advisory Council on Aging. Expression, Newsletter of the National Advisory Council on Aging, Vol. 11, Number 3, Spring 1998.

Canadian Palliative Hospice Care Association www.chpca.net

Code of Ethics of the Canadian Medical Association. CMAJ 1996

Comments by Michael MacLean, director of Age Wise Inc.,

Handbook for Mortals: Guidance for People Facing Serious Illness by Joanne Lynn, M.D. And Joan Harrold, M.D.

Canadian Hospice Palliative Care Association – Hospice Palliative Care
https://www.chpca.ca/about-hpc/

MAID https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html

National Caregivers Library, End of Life Issues, 2013

Karen Roosen, Director of Client Services for the Community Care Access Centre of Renfrew County in Ontario.

Planning for the End of Life, The Canadian Institute of Chartered Accountants, 2013

Time Line of assisted suicide in Canada: https://www.cbc.ca/news/health/timeline-assisted-suicide-in-canada-1.2946485

The Right to Die Society of Canada, 2013 https://www.cbc.ca/news/health/timeline-assisted-suicide-in-canada-1.2946485

www.righttodie.ca; www.virtualhospice.ca

This page intentionally left blank

Chapter 5

Funeral Planning

---

5 - 1 KEY OBJECTIVE OF THIS CHAPTER

For most of us, dying and funeral planning are far from "top of mind." As we age, however, our focus tends to change. Close friends and associates start dying with regularity. The obituaries become "must see" reading. Visitations and funerals become a normal part of our monthly routine.

The following material will give you a basic understanding of funerals and funeral planning. In the process you will also get a peek into the daily lives of most Canadian elders. Understanding their daily reality cannot help but make you more effective in dealing with them.

5 - 1.1 How Will This Objective Be Achieved?

We will take an in depth look at funerals and the funeral planning process. We will cover such basic topics as: disposition of the body; funeral products; funeral service options; and funeral costs. Several other, less obvious, topics (e.g., choosing a funeral provider, disposing of personal items, funeral regulations) will also be covered in some detail.

5 - 2 INTRODUCTION

When a loved one dies, grieving family members and friends are confronted with dozens of decisions about the funeral. These decisions must be made quickly and often under great emotional duress. What kind of funeral should it be? Which funeral provider should be used? Should the body be cremated, buried, or donated to science? Which services are optional and which ones are mandated by law? What other arrangements need to be made? And, as callous as it may sound, how much is it all going to cost?

Each year, Canadians grapple with these and many other questions as they spend billions of dollars arranging tens of thousands of funerals for family members and friends.

The increasing trend toward pre-need planning—when people make funeral arrangements in advance—suggests that many consumers want to compare prices and services so that the funeral can be meaningful, fulfilling and the product of a wise and well-informed purchasing decision.

5 - 2.1 A Consumer Product

Funerals rank among the most expensive purchases many consumers will ever make. A traditional funeral in Canada, including a casket and vault, cost on average just short of $10,000 in 2017. Many traditional funerals, however, run well in excess of $10,000.

Yet even if you are the kind of person who might haggle with a dozen dealers to get the best price on a new car, you are likely to feel uncomfortable comparing prices and negotiating when it comes to funeral services - whether they be pre-need or at need.

A large segment of the population feels compelled to "overspend" when it comes to funeral services, caskets, vaults and burial plots. Overspending is their way of demonstrating their feelings for the deceased.

5 - 2.2 Provincial Regulation

Funeral providers are professionals who strive to serve their clients' needs and best interests. Nevertheless, in the past, some have been known to take advantage of their clients through inflated prices, overcharges, double charges, or unnecessary services. Fortunately, there are laws that make it easier for consumers to choose only those goods and services they want or need, and to pay only for those they select, whether arrangements are made on a pre-need or at need basis. In short, regulations have ensured that the funeral industry is almost universally above board when it comes to the treatment of it’s' clients.

Every province has regulations in place that require funeral directors to provide an "itemized written price list" - covering all their goods and services - to anyone who requests it in person. Information concerning the prices of various goods and services must also be provided to individuals who request this information over the phone. Provincial regulations also place other consumer friendly demands upon funeral homes. If the consumer wants to buy a casket or other burial container, for example, the funeral provider must show them descriptions of all the available selections and their prices before showing the caskets or containers.

Many funeral providers offer “packages” that include a variety of different goods and services. Every consumer, however, has the right to buy any of a given funeral home's various goods and services on an individual basis. No one must accept a package that may include many unwanted items.

All the following funeral regulations apply, from coast to coast:

- ❖ With few exceptions, consumers have the right to choose the funeral goods and services they want
- ❖ The funeral provider must indicate that this is a "consumer right" on his or her general price list
- ❖ If provincial or local law requires that the consumer buy an item, the funeral provider must disclose this on the price list, with a reference to the specific law involved
- ❖ No funeral provider may refuse - or charge a fee - to handle a casket that has been purchased elsewhere
- ❖ Any funeral provider that offers cremations must make alternative containers available

5 - 2.3 Are Funeral Homes Mandatory?

Surprisingly, there is no law that states that consumers must use a funeral home. However, for a wide variety of reasons, it is probably best to put the matter into the hands of a trained professional.

Most people are not equipped, either physically or emotionally, to handle such things as body storage, transportation and - in cases where burial or cremation is not immediate - body preservation. They are also unlikely to understand the regulations governing funerals, the permits required, and the complex logistics involved in managing the entire process.

5 – 3 DO IT YOURSELF FUNERALS

Before the 20th century, it was common for people or communities to take care of their own dead — both before and after the death. Most people died at home, supported by friends, faith communities, or the local midwife (who often attended both births and deaths). Sometimes doctors attended the death in the home — but primarily to witness it and offer support.

Post-death care — washing and dressing the body — by the family members was considered a ‘last act of love and/or respect’. The community helped organize a time of “lying in honour”, final farewells, or wake, where friends would come to the home and offer their last blessings to the deceased and condolences to the family. A friend or family member usually made the coffin or shroud; others would dig the grave and then help fill it in after the coffin was lowered into it.

The parish clergy — who mostly likely knew the deceased and their family well — would do the traditional funeral service; but if that were not appropriate or available, the family would create the service themselves. Tradespeople would often make the coffin and the gravestone; but other than that, most of the death care and arrangements were done by the family/community.

Even in cities, where there was likely to be a local undertaker who would dig the grave and transport the body to it, the post-death care still happened in the home.

In fact, this approach to post-death care has only been lost for a few generations — many older people remember their grandmothers taking the equivalent of a "death midwife" role in their family or community. Many non-Western, ethnic or religious traditions around the world have preserved this kind of post-death care to the present day — and it is also still maintained in many rural areas of North America.

Towards the end of the 20th century, people began to question the current funeral practices for several reasons — ecological concerns, expense, and the loss of the ability to carry out the deceased's wishes. In addition, without a hands-on approach, a significant part of the opportunity to process grief and other emotions is lost — although in fact the family may not be aware of that at the time. As a result, many people are considering other options — including those which are more family-directed, hands-on, personally meaningful, as well as usually less expensive — such as "home funerals."

5 – 3.1 History of Funeral Homes and Services

Embalming became popular during the American Civil War, to be able to transport soldiers' bodies' home to be buried; and it became even more popular after the Second World War for the same reasons. It eventually expanded into the commonplace practice that it is today. The skill of embalming required special training and certification, as well as the necessary equipment and a place to house it. Especially in cities, it soon became more convenient to hand over post-death care/arrangements to a funeral director.

Much of the cost charged by today's funeral homes is, of course, entirely justified. It is expensive to maintain a funeral-home, equipment, and a range of products, as well as an on-call funeral director (prepared to pick-up the body within an hour's notice of death) — services which are usually included in the "basic arrangements" fee.

However, many of the services that have now come to be considered "standard" (embalming, ornate coffins, and various other "optional" products) are merely add-ons. Many people have, however, comes to believe that these add-on services are essential – not optional.

As the industry grew, so did the range of secondary products and services that funeral homes offered. Extra services — like arranging for flowers, filing the obituary, transporting the body and supplying limousines for the family, providing pallbearers, having mementos available for those who attended the ceremony, planning with third parties (clergy, cemetery/crematorium, etc.) — may be included in the total fees.

The ‘death taboo’ of our culture forbids us to speak about death at all, except in the most indirect and roundabout terms.

This taboo added to the tendency of Canadians to “go with the flow” and “keep up appearances” results in most people concluding that it is inappropriate (perhaps even undignified) to consider the cost of various funeral options. Both constraints result in a reluctance to question the necessity or the value of the options available.

Some people even consider that you can only truly honour the dead by opting for the full range of services and products. Unfortunately, because of these cultural norms many family members will often insist that the deceased deserves the very best, to the point of shaming the decision-maker into that choice.

As a result of both the expense and pressure to buy options, many people are now opting for “direct cremation” — which is generally a quarter the cost of a medium-option burial. In this case, the body is removed from the home, hospital, or residential facility; stored in the funeral home’s morgue for the required 48 hours; and transported to the crematorium — without any visitation, funeral service, or other involvement by the family/friends.

5 – 3.2 Where to Start

All the post-death care and arrangements can be done by the family and friends at home. Cooling the body to the required temperature is easily achieved using dry ice or Techni-Ice gel packs (which need to be ordered in advance). Burial or cremation arrangements can be made directly with the cemetery or crematorium. All arrangements for visitation/final farewells, and funeral and/or memorial ceremonies, can be planned by the family/friends, with or without the leadership of clergy or spiritual advisors. All the legal paperwork is available on-line from government sites and can be filed directly with your local Vital Statistics office — although special body-transport permits, if required, are usually obtainable from Consumer Protection Agencies.

5 – 3.3 The Benefits

If a funeral home is used, the body may be taken away as early as an hour after death. Open coffin funerals are becoming less popular; and most funeral homes require that the body be embalmed for this type of funeral.

Unless the family is willing to pay the extra cost of visitation, they — and those travelling from a distance for the funeral — will not see the body again and have no opportunity to say their final farewells. As a result, there is no tangible evidence of the reality of the death; and even if visitation or an open coffin is allowed, cosmetics will be used to make one is loved one look like they are only sleeping. As a result, the family and friends may be left in an emotional never land, which can become a significant obstacle to moving through the healthy stages of bereavement.

Although there is a cultural taboo when it comes to handling the body, many of us have held the hand of our loved ones or kissed their forehead shortly after they died.

Post-death care (washing and dressing the body before rigor mortis sets in) is not significantly different from pre-death care, especially if we have been caring for our loved one throughout their final days — except that we no longer need to worry about hurting them. Doing the post-death care is a time-honoured gift of love and respect that has been maintained by ethnic and religious cultures across the world. For those who have been caregiving pre-death, it is a brief period of extended caregiving — time to tend their loved one for one last time, and gently transition out of the caregiver role. For those who live at a distance or were not otherwise able to help with the pre-death support, it is an opportunity to participate in the last act of caregiving.

Keeping the body at home allows the family/friends to explore what ceremonies or customs would be most significant to them or their dead loved one; and to arrange for what is most personalized and meaningful to them and do so in their own timing. Such ceremonies/customs can also include children in appropriate ways and allow them to come to their own terms with what death means — which are generally healthier and more inventive that we would have guessed.

Making the coffin or shroud, and/or decorating a standard cardboard coffin in a personalized manner, allows others to be involved in the post-death process — especially those who are not prepared to do physical care themselves, or who were unable to arrive in time. It is another variation of a final gift; and can provide an evocative means for both releasing grief and reconnecting with family/friends — as well as something else which children can directly participate in.

5 – 3.4 Family-Directed Funeral or Memorial Ceremonies

In the past, by North American custom, the local parish clergy would lead the funeral service, according to the family’s religious tradition. Nowadays, fewer people belong to a faith community: and family members may follow very different religious/spiritual traditions and lifestyles from one another. Likely, the funeral director also has no direct knowledge of the deceased, except what is conveyed by the family in a stressful and limited time period. Most of us have experienced a funeral service where the clergy or funeral director did not know the deceased, and/or was following a tradition that the deceased did not belong to and perhaps even disagreed with.

Direct cremation is becoming more and more popular — in part because it is the least expensive way to deal with the remains. However, it generally does not allow for any direct family involvement — although it is sometimes acceptable for a family member to push the button (starting the cremation process), but usually only if they specifically ask to do so. Modern families may only have a memorial service, sometime later than the burial or cremation — often this is in the form of a "celebration of life." While these services offer a large community of family, friends and acquaintances the opportunity to honour the life led by the deceased, they do not provide the intimacy of both grief-sharing and the tangible honouring of the deceased that a service directly connected to the cremation or burial does.

A family-directed funeral service (either as part of the burial or cremation process, or later) allows the family to explore what is particularly meaningful to them. If the deceased is conscious and aware before death, they can be directly involved in choosing the most significant elements of the ceremony.

Memorial services — whether there was a funeral service directly connected to the burial or cremation — are often added later to allow for a broader community to gather together and celebrate the life of the deceased. They are most often arranged by the family and led by a friend; and may be in a rented hall, a meadow, etc. — anywhere that fits the family's needs, and/or that may be special to the deceased.

5 – 3.5 What Help or Advice Is Available?

The Canadian Integrative Network for Death Education and Alternatives maintains a website with all the necessary information and resources (for each province/territory) to handle post-death care, arrangements, and the legal paperwork — without using a standard funeral home. The website also provides listings of Canadian alternative death-care practitioners who can provide support through the process.

In addition, although U.S. based, both the National Home Funeral Alliance (NHFA) and the Funeral Consumers Alliance (FCA) support the rights of families to direct their own post-death care and funerals and have information on how to do so.

5 - 4 PLANNING IN ADVANCE

To help relieve their families of the burden of arranging a funeral, an increasing number of people are planning their own funerals, designating their funeral preferences, and sometimes even paying for them in advance. They see funeral planning as an extension of will and estate planning.

In the absence of pre-planning, the family will need to make decisions quickly about caskets, location of burial, services, announcements, and so on.

For many the period just after a death is not a good time to be making crucial decisions and negotiating the price of a variety of costly services. It is often much too easy to spend more than what is warranted and more than what the deceased would have wanted. This, of course, is why federal and provincial regulations were put in place requiring funeral home directors to give customers notice about the costs of services, about which services are legally required, and about the full range of casket options.

The overwhelming number of issues that arise just after death and the risk that poor decisions will be made in haste, has led many people to consider the benefits of pre-need planning.

It may seem terribly uncomfortable to be arranging a funeral for someone who is still alive, but it certainly helps to ensure that prudent choices are made and that the family is under substantially less pressure than during the emotionally difficult time just after death. Thinking ahead can help ensure that informed and thoughtful decisions are made. Pre-planning also allows people to have some input into their own funerals; to compare prices from several different firms; and to help spare the survivors the stress of making funeral decisions while distraught and under significant time pressures.

Pre-need planning can be done directly with a funeral home, or through a funeral planning or memorial society (i.e., a non-profit organization that provides information about funerals and disposition - but that does not offer funeral services). Most memorial societies focus on planning simple and cost-effective funerals. If you choose to work with a funeral planning or memorial society, it is worth noting that even though some funeral homes may include the word ‘society’ in their names - they are not one of these non-profit organizations.

Also keep in mind that it is possible to make decisions about funeral arrangements in advance, without any requirement to pay for them in advance. Whether to pay upfront, or not, is heavily dependent on an individual's financial circumstances and their read on the marketplace. The cost of a funeral can go up, or under certain circumstances, down, depending on the level of competition in each area. In addition, it is important to remember that circumstances change (e.g., businesses close, ownership changes, people move). As a result, it is a good idea to review and possibly revise any plans that have been put into place every few years.

It is always a good idea to indicate an individual's preferences in writing and to ensure that copies are given to family members. In addition, it never hurts to keep a copy of these preferences in a handy place. Preferences should not be covered in one is will - since the will may not be reviewed until after the funeral. It is also advisable to avoid putting these written preferences in a safety deposit box - for the contents of safety deposit boxes are rarely examined until well after the funeral.

5 - 4.1 The Benefits of Planning in Advance

- Rational and logical decisions can be made at an unemotional time
- It allows abundant time for comparison shopping
- Collaboration - between family members and loved ones - is possible
- The elder can obtain the peace of mind that comes with knowing that their wishes are known and that these wishes will be carried out as specified
- Both the financial and the emotional impact of the funeral (on the survivors) can be minimized
- Prepaid services offer the benefit of tax sheltering

5 - 4.2 A Pre-Planning Checklist

The following checklist is a handy tool that can be used, while visiting various funeral homes, during the pre-planning process. It focuses on the types of services available, and their costs.

Table 5 – 1 Service and Price Checklist

PRODUCT OR SERVICE REQUIRED	Home 1	Home 2	Home 3
"Simple" disposition of the remains			
Immediate burial			
Immediate cremation			
If the cremation process is extra, how much is it?			
Donation of the body to a medical school or hospital			
"Traditional" full-service burial or cremation			
Basic service fee for the funeral director and staff			
Pickup of body			
Embalming			
Other preparation of body			
Least expensive casket			
Description, including model #			
Outer Burial Container (vault)			
Description			
Visitation/viewing - staff and facilities			
Funeral or memorial service - staff and facilities			

Graveside service, including staff and equipment			
Hearse			
Other vehicles			
TOTAL			
Other Services			
Forwarding body to another funeral home			
Receiving body from another funeral home			
Cemetery/Mausoleum Costs			
Cost of lot or crypt (if you do not already own one)			
Perpetual care			
Opening and closing the grave or crypt			
Grave liner, if required			
Marker/monument (including setup)			
TOTAL			

Make copies of the above checklist and be sure to check with several funeral homes in your area to compare costs.

5 - 5 CHOOSING A FUNERAL PROVIDER

As noted above, there is no legal requirement to use a funeral home to plan and conduct a funeral. However, for a wide variety of reasons, most people elect to work with a funeral director and funeral home.

Consumers often select a funeral home or cemetery because it is close to home, has served the family in the past, or has been recommended by someone they trust.

As one prominent Canadian funeral operator has noted, just like the patrons of the bar in the television series "Cheers," people are looking for a funeral home "where they know my name."

Having said this, people who choose to limit their search to just one funeral home, severely reduce their options and put themselves at considerable risk of paying too much.

Comparison-shopping need not be difficult, especially if it is done on a pre-need basis. Price comparisons can be conducted either in person or over the phone.

As noted above, no arm twisting is required in order to obtain pricing information from a variety of different funeral homes. In comparing prices, be sure to consider the total cost of all the goods and services together, as well as the price of individual items. Also, be cognizant that funeral packages can be both good and bad. If a package has precisely the services you desire, it may offer a significant price advantage over purchasing the items individually. However, if the package offers several unwanted goods and services it may not offer particularly "good value."

When comparing the offerings of several different funeral homes, also keep in mind that there is a growing trend toward consolidation in the funeral home industry. What appears to be a competitive market (due to a proliferation of different operators) may be nothing of the sort. Many neighbourhood funeral homes, thought to be locally owned, are in fact a part of very large conglomerates. If this issue is important to an individual, a bit of leg work and investigation may be required.

5 - 6 DEALING WITH THE BODY

It will be up to the family to make decisions about how the body of the deceased will be handled. Who will provide funeral services, and will this involve a cremation or a burial?

Additional questions also arise. Will the body be buried or cremated immediately, or will there be a delay (to allow for visitation)? In the case of a delay, some form of preservation will likely be required.

What happens after the visitation and church service? Has a burial plot been chosen and if so, will the casket be placed in a vault (i.e., a grave liner - often made of concrete - which completely encloses the casket)? Or will the body be placed in a crypt in a Mausoleum? Even more choices are available in the case of cremated remains. Will disposition (i.e., placing the remains in their final resting place) involve burial, an urn on the family's mantle, a niche in a columbarium (a structure designed specifically to hold cremated remains), or will the remains be scattered in a special place?

Cremation, it should be noted, is becoming increasingly popular - perhaps because it is much less expensive than a traditional burial. Families may require nothing more than a service to transport the body to a crematorium and then return the ashes.

In other instances, dealing with the body may be anything but easy. Transporting remains - particularly if international borders are involved - can be especially tricky. The family will need to have a funeral director in the city where death occurred, and another funeral director in the city where the burial will take place.

International, long distance transportation of a body is a complicated process that will require assistance from the Canadian Embassy abroad and skilled funeral directors at each end of the transaction.

5 - 6.1 Time of Death until Burial or Cremation

In some traditions, burial should be very prompt, within one day of death. In others, burial does not take place for a few days, in order to allow family and friends to gather. Thanks to modern refrigeration and embalming techniques, a few days of delay are a perfectly acceptable option.

In some traditions, a prolonged period of praying (often weeks or longer) with the body present is considered optimal. This poses several challenges, and practices of this nature often create considerable friction with public authorities.

Most funerals and burials, however, occur within the span of one week. In fact, it is increasingly common to proceed with burial or cremation within a few days at most - and then hold a more thoughtfully planned memorial weeks or even months later.

5 - 6.2 Accommodating Religious Tradition

The increasingly multicultural face of modern day Canada has brought a variety of new funeral rites and traditions into the mainstream. Most funeral homes are more than willing to accommodate these variations - with two notable caveats. Funeral homes will not allow any practices to be conducted on their premises that are either illegal or undignified.

As odd as it may sound, some religious traditions call for an abundance of close personal contact with the body of the deceased. Fortunately, there is rarely any health reason that family cannot be in contact with a dead body, so those who are moved to participate, for example, in bathing the body in preparation for burial are more limited by popular squeamishness than by real risks. Those who do help with bathing or dressing the body often find it to have been an important labour of love and a significant milestone in coming to terms with the death. As noted, most funeral homes are more than willing to accommodate religious traditions of this nature.

Many people today are only vaguely familiar with the rituals of their own traditions - and a funeral presents them with an opportunity to reconnect. The event facilitates personal reflection and offers lots of contact with their religious leaders.

It should also be stressed that a funeral home's willingness to "accommodate" is not limited to religious practices. They are also quite receptive to the specific requests of the family and/or the deceased. In our highly individualistic society many people - whether they are religious or not - are looking for ways to make their own mark - to set themselves apart from the crowd. The funeral home is there to help. Almost anything goes - so long as it is dignified and legal.

5 – 6.3 Donating the Body to Science

Another - extremely cost effective - way of dealing with the body involves donation of the body to science. A variety of institutions across the country are quite willing to accept donations of this nature.

Once the institution's use of the body is complete (approximately 18 months to 3 years following the receipt of the body) cremation will take place.

The cost of cremation: transfer of the body from the institution to the crematorium, the coroner's cremation certificate fee and cremation fee are typically all covered by the institution.

Once cremation is complete, the next of kin will be contacted, by letter, and advised that they can retrieve the cremated remains.

Body donation is an option for anyone at any age. The final decision ultimately rests with the next of kin or the executor, as they will be the ones to carry out the steps required for body donation, also known as bequeathal. As such, a person interested in donating their body should include this in their will, letter of last instruction, and funeral pre-arrangements. It should also be shared the family and executor.

Donors should be aware that while most bodies bequeathed to programs of this nature are accepted, there is no guarantee. Programs of this nature will decline, or refuse, individuals who: have infectious diseases, have had recent major surgery, are morbidly obese, have been embalmed, have been major organ donors, have recently experienced severe trauma, die outside of their home province, have had amputations, have been dead for more than 48 hours or have a family member who objects to the bequeathal of their body.

Considering this, individuals who are considering body donation should have alternative funeral plans in place should the program decline the donation.

5 - 7 TYPES OF FUNERAL

Every family is different and as a result not everyone wants the same type of funeral. As noted in previous sections, funeral practices are influenced by religious and cultural traditions, costs, and personal preferences. These factors help determine whether the funeral will be elaborate or simple, public or private, religious or secular.

The above factors also help to determine where the funeral will be held, whether the body will be present, if there will be a viewing or visitation and, if so, whether the casket will be open or closed.

5 - 7.1 “Traditional” Full Service Funeral

A "traditional" funeral usually includes a viewing or visitation, a formal funeral service, use of a hearse to transport the body to the funeral site and cemetery, and burial, entombment or cremation of the remains.

It is generally the most expensive type of funeral. In addition to the funeral home's basic service fee, a traditional funeral usually involves embalming costs, room rentals for the visitation and viewing, the use of limousines, casket purchase or rental and other funeral goods and services. In addition, there are often significant cemetery fees (e.g., the cost of the plot, grave opening and closing, ongoing maintenance, markers, etc.). Some cemeteries insist on the use of a full grave liner - usually made of concrete - that fully encloses the casket, and which therefore reduces ground settling.

5 - 7.2 Direct Burial

With direct burial, the body is buried shortly after death, usually in a simple container. No viewing or visitation is involved, so no embalming is necessary. A memorial service may be held at the graveside or somewhere else later. Direct burial usually costs somewhat less than a traditional, full-service funeral.

Costs are limited to the funeral home's regular service fee, basic transportation costs, the purchase of a simple burial container, and a cemetery plot or crypt. If the family chooses to be at the cemetery for the burial, the funeral home often charges an additional fee for a graveside service.

5 - 7.3 Direct Cremation

With direct cremation, the body is cremated shortly after death, without embalming. The cremated remains are then placed in an urn or other container. No viewing or visitation is involved, although a memorial service may be held, with or without the cremated remains present.

Although cremation as a disposition option has been around in Canada for some time, the interest in simple, low-cost alternatives is growing. Changing religious and cultural attitudes and the effects of the recession have resulted in more Canadians looking for less expensive and simpler alternatives to a full cremation service. This is the least expensive means by which to conduct a funeral. It can even be arranged online, without the need to visit a funeral home.

According to the Cremation Association of North America (CANA) the cremation rate in Canada is currently 70.5% (compared to 35% in 2000 and only 6% in 1970) making cremation by far the popular choice for families today.

As noted, cremation is much less expensive than burial — generally about 1/4 of the cost of burial if it is a simple/direct cremation.

A simple, direct cremation in Canada can start at around $600.

The difference in cost is also influenced by the fact that many of the burial grounds in Canada are full; and there is no remaining land, within city limits, to establish a new one — hence burial costs are rising. Because of the lower cost, many Canadians assume that cremation is also the more ecological option — unfortunately, it is not.

The pollution resulting from one cremation is 5 times that of burial; and is estimated as equal to at least a 500-mile car journey (other sources suggest a trip across most of the breadth of Canada). Mercury from dental fillings is often dispersed into the air unless the crematorium has special filters to remove it.

Two options to cremation that are more ecologically friendly have been invented — Resomation (also called Bio-Cremation), which liquefies the body with an alkaline solution; and Promession, which freeze-dries the body. Unfortunately, these two options are not yet available in Canada, although Transition Science claims to have the license for the distribution of Resomation equipment in Canada. There are at least two active Resomation facilities in the U.S., and more in Britain, where the technology originated. In all cases — cremation, Resomation and Promession — the bones still need to be pulverized before being given back to the family.

One of the most difficult decisions facing loved ones after a cremation is what to do with the cremated remains. A variety of options are available.

A family may choose to inter the urn in a new grave selected by them. Many cemeteries offer small graves for cremated remains - often within the confines of a memorial garden. Alternatively, the family may opt to purchase a full size grave or bury the urn in an existing family grave site. Burying the remains will add significantly to the cost of a direct cremation, as will any formal graveside services have planned during the interment.

Some families find the idea of burying, either a body or cremated remains, distasteful. Choosing cremation allows them to forgo any sort of burial. Instead, the urn containing the cremated remains can be placed above ground in a structure called a columbarium.

Columbaria are designed to house many urns. The family selects either a single niche or perhaps a double niche, within the columbarium, to hold the urn(s). A permanent memorial with the decease's name and other information is placed next to the niche.

A columbarium may be a simple free-standing wall located outside that is adorned with trees, shrubs, flowers, and benches - or it may be in a mausoleum or other building.

Another option available to the family involves scattering the cremated remains. This option, however, should only be considered after a great deal of thoughtful reflection. Many families that chose to scatter cremated remains end up regretting it afterwards.

Scattering is permanent and once it is done it cannot be reversed.

There are endless options to where ashes may be scattered. In general, ashes can be scattered anywhere — except that in a park or private land, a permit or written permission must be obtained. If a sea-scattering is preferred, find out what the regulations state in your area — usually several nautical miles from the shore.

Occasionally, the memorial service is directly connected to the spreading of ashes — either at the site of the spreading, or just beforehand in a suitable hall; and friends may or may not be invited to also attend the spreading afterwards. More often, one or more members of the family spread the ashes sometime before or after the memorial, in a more intimate ceremony that they have designed themselves. One option is to divide the ashes amongst family members and maintain them for a year's time; and then share spreading them in a family gathering, which acknowledges the first year anniversary, and tends to be a particularly difficult date in the grieving process. However, any option that is meaningful to the family can be chosen. In 2014, for example, Canadian skier Sarah Burke's ashes were spread in Sochi, in the Olympic halfpipe, high on a mountain above it and near the Olympic rings in the athletes' village.

Burke, considered a pioneer for the introduction of halfpipe and slope style into the Winter Games, died following a training accident in Utah in January 2012.

Freestyle coach Trennon Paynter from Squamish, B.C., distributed Sarah's ashes prior to the competition. "That was a little bit of a stealth mission," he said at the time, "I feel pretty good about knowing Sarah was all over these Olympics in our hearts and quite literally too."

Families often decide to scatter the remains on their own private property - a decision that can make selling the property, later, very difficult. Others opt to spread the ashes at a favourite place (e.g., a park or golf course) and run the risk that the location will become slated for redevelopment at some later date.

A safer bet may be to make use of the scattering gardens that are available at many cemeteries. This eliminates the risk of redevelopment and offers families the option of erecting a memorial.

As well, families need to be aware that the physical act of scattering remains can, itself, pose certain problems. Cremated remains are often quite course with bits of bone remaining in the mix. Not all the remains will drift off into the wind. In addition, in situations where the remains are scattered over the water, they tend to settle on top of the water, rather than mixing in with it. Finally, it should go without saying that participants should take careful note of both wind velocity and wind direction before attempting to scatter cremated remains.

A final option available to families is to simply take the urn home with them - either on a temporary or a permanent basis. Doing so may help them to feel close to the deceased and assist in their grieving process. However, keeping an urn at home may create other issues - not the least of which is the risk of theft and or vandalism.

5 - 7.4 Cultural Variations

The type of funeral chosen will be heavily dependent on cultural and religious tradition. Roman Catholics, Anglicans and Eastern Orthodox Christians are quite likely to opt for a full traditional funeral including a church service with the body present. Muslims tend to hold a service - usually very shortly after death - at either the home of the deceased or at a mosque. This service is then followed by burial - with the body covered by a shroud and placed in the grave site such that it faces Mecca). Others - particularly recent European immigrants - are likely to hold a traditional wake (a vigil conducted over the body) at the home of the deceased.

Whether the body is cremated or buried is also heavily influenced by religious and cultural tradition. Many religions allow for either the burial or cremation of the deceased. Some religions (e.g., Jewish, Muslim, Mormon, Eastern Orthodox), however, frown upon cremation - while others (e.g., Hindu, Buddhist) strongly encourage it.

Many religions also call for a period of formal mourning to be held after the funeral. In some traditions the surviving spouse must wear black clothing for up to a year after the funeral. In other traditions (e.g., Jewish) a full week of mourning - in which the immediate family has little or no contact with the outside world - is mandated.

The following material looks at the funeral traditions of a variety of different religious groups.

Buddhist

Buddhist funeral services vary considerably, depending on which country the believer is from. Most Buddhist funerals take place in a funeral home, not a temple.

Ritual chanting may begin at the placer of the deceased’s death and continue throughout the service. The evening before the day of the funeral, visitation (viewing the body) is held. Inside the funeral home, a table is set up with candles and incense, which will burn until the body is moved to a cemetery for burial or cremation. Food and incense are left on the table as an offering to the deceased and to the gods.

The family sits at the front of the room in which the casket is placed. Visitors greet them, offering their condolences, then go to the casket and bow. Well-wishers can either stay and sit for a while, or they may choose to leave. Although sending flowers and donations are not a Buddhist custom, it is acceptable to do so. There may be a white cloth or carpet on the floor in front of the casket. While the family wears white (the colour of grieving), friends often wear black. In the funeral home, shoes can be left on. Footwear is removed only in temples.

Some funeral homes are equipped with special fireplaces in which people burn pretend money and/or paper images or material objects particularly meaningful to the deceased. This is to help the deceased on his or her journey.

The funeral service is held the following day and is traditionally conducted by a monk or a nun. Visitors are not expected to participate in prayers or chants. Men and women can sit together and are not required to wear a head covering. At the conclusion of the service, visitors come forward in groups and bow before the casket as a way of showing their final respect.

Either at the funeral home or at the cemetery, guests may be given an envelope which contains a coin, for good luck, and a candy to help take away the bitter taste of death. It is usually preferred that the casket not be lowered at the cemetery in front of the family members.

After the service at the cemetery, family and close friends usually gather at a restaurant, where they share a meal

Catholic

There are many cultural variations in the practice of Catholicism, but there are also some constants. Anointing of the sick prior to death is usually considered important.

The body of the deceased is usually viewed in a funeral home and then transported to a church for a funeral mass.

At the funeral home, a Priest, or other designate, officiates over prayers. Visitors may join in or sit quietly; it is considered disrespectful to talk or leave. The prayers last about 15 minutes.

In church, Catholics genuflect before entering their pew. This is a gesture which non-Catholics should not imitate. The casket is usually closed at church and may be draped with a religious pall. The funeral pall emphasizes the fact that we are all equal in the sight of God. During the funeral mass, the priest will extend an invitation to those who should take communion. Everyone should rise and sit at the appropriate times. Also, if visitors are familiar with the hymn being sung, they may join in.

It is appropriate to send flowers, cards and to make donations to charitable organizations on behalf of the deceased. It is also customary for Catholics to obtain Mass cards, which are displayed at the funeral home. These signify that a mass will be said in memory of the deceased. It is requested that those obtaining Mass cards include a stipend to the church.

A procession to the cemetery will follow the mass, where a burial customarily takes place. While the Catholic Church does not forbid cremation, it strongly recommends burial.

A reception at the church hall or a community centre usually follows the burial.

Hindu

Hindus prefer to hold the funeral rites before the sun goes down on the day of death. Traditionally, the first born son presides at the service with the Hindu priest.

The service is held at a funeral home. It is appropriate for flowers and donations to be sent, although this is not a part of the Hindu tradition. While mourners wear white, visitors are asked to wear subdued colours.

At the funeral service, the family may put flowers on the deceased. Sentiments vary depending on the circumstances of the death. If the person is old, he or she is regarded as being blessed, as having led a full life, and the soul is ready to return to God. As a result, there is little outward grieving at such a funeral. A thread may be tied around the neck or wrist of the deceased as part of the ritual blessing and should not be removed by family or well-meaning friends.

At the crematorium (all Hindu adults are cremated) another short service takes place. Deceased children are usually buried. Afterwards, the family is expected to enter a period of formal grieving which can last 13 days or longer (depending on their caste in society). At the end of that time, the family sponsors a feast for close friends and relatives.

The cremated remains of the deceased are usually taken back to India to be scattered in the Ganges River, or another method of final disposition may be chosen.

Humanist/ Non-Religious

Humanists refer to a funeral as a ceremony rather than a service. They see the event as a way of providing support and comfort to the living rather than as a ‘service’ to a higher being.

Humanist ceremonies are personal celebrations of an individual’s life. There are no rules on how to conduct them. Each ceremony is tailored to the taste and wishes if the family and to the personality of the deceased. They may involve music, poems, readings of favorite books, as well as short eulogies by friends. The content of these commentaries centers upon the ways in which the person’s life enriched and strengthened the lives of others.

Giving a gift of flowers or making a charitable donation is a proper gesture.

Islam

Muslims try to bury the deceased as soon as possible after the death has occurred. Typically, this is within 24 to 48 hours. Cremation is strictly forbidden.

A purification ritual takes place immediately. This cleansing ceremony is performed in private by appointed specialist who is of the same sex as the deceased. The body of the deceased is washed, wrapped in a shroud and will be placed in a simple wooden casket. The funeral service may take place at either a mosque or a funeral home. It is a simple ceremony and because of the Islamic belief that one comes into the world with nothing and should go out of the world with nothing, it is completely free of gifts of any kind.

At the mosque, men and women sit in separate area. It is appropriate for visitors to do so also. You may be expected to remove your shoes. Visitors are not expected to participate in prayers. As for dress, all parts of the body should be covered. This applies to both men and women. There may be colour restrictions.

Women are not obligated to attend the graveside service. They attend the graveside every week until the forty-day mourning period is complete. An Imam (Islamic priest) conducts the service at the cemetery to ensure that the deceased is properly placed in the grave. The head of the deceased must be facing east so that the deceased may complete the directives of Allah.

After the burial, there is no formal reception, but it is appropriate to offer condolences to the family, though not necessarily right afterwards (the time varies with the wishes of the family). It is not appropriate to send flowers. However, memorial donations are acceptable.

Judaism

Jewish funerals take place as soon as possible after death, sometimes the same day. Embalming the body is considered disrespectful and the body is not put on public display. Well-wishers pay their respects by attending the funeral service at the synagogue or chapel, participating in the burial at the cemetery, and supporting the family during the week of Shiva following burial. Shiva is a time when the family can withdraw from its social and communal responsibilities in order to grieve.

While the observance of Judaism covers a wide range of practice (Orthodox, Conservative and Reform), the actual funeral services are very similar. Until burial, the focus of the funeral service is centered around the deceased. As a result, it is not appropriate to approach the family to offer condolences until the body is buried. (Cremation is not permitted in traditional Judaism and, while it is tolerated by reform Jews, it is not encouraged.)

The funeral service may be conducted by a Rabbi and Cantor, although family and friends might also participate. The service, which lasts 12 to 15 minutes starts and ends with readings from Psalms. The main part of the service is the eulogy recounting the life and good deeds of the deceased.

At the cemetery, there is another short service. Visitors might be asked to participate by helping shovel earth over the casket.

Sending flowers is not a Jewish tradition. Instead, a donation to the family's favorite charity or cause is a sign of honor and respect for the memory of the deceased.

Following the burial service, friends and well-wishers are invited to the family's home, where they may partake in a meal symbolizing the notion that, even at this darkest time, life is precious and must be nurtured. During the week of sitting Shiva, friends are expected to visit the family to bring comfort and to share in their grief. On the anniversary of the death (Yahrzeit), a memorial lamp will be lit, and the family will participate in prayers and acts of charity. A ceremonial unveiling of the memorial maker generally takes place with the first year after death.

Native Canadians/Aboriginals

Native Canadians do not have a single unidentifiable faith. They are peoples with diverse and rich religious traditions. The foundation of their deeply spiritual views are based on traditional beliefs and values. Native Canadian beliefs will often reveal a deep respect for their elders.

It is impossible to generalize about Native Canadian beliefs, for their values are related to their sense of sacred.

Many Native Canadians believe that death is the beginning of a journey into the next world. One's spirit often needs help to make this journey. Consequently, strict rules often govern the behavior of the relatives of the deceased. Such rites ensure their loved ones a good start in their journey to the other world.

While Native beliefs assert that death is not necessarily the termination of life, the bereaved still mourn the absence from this life of the one who has died. It is improbable that you would arrive at the funeral as an "outsider." It is more likely that you would be invited to attend the ceremony. It is important that you express your sympathy and empathy to the bereaved. Respectfully keep your distance and view the ceremony as a personal experience shaped by a community-based ritual.

Consult Family members of the deceased, band leaders or the funeral directors for appropriate protocol.

Orthodox

The funeral traditions do not vary greatly between Russian, Ukrainian, Greek, or African Orthodox, but obviously, language does. The funeral usually takes place three days after the death. The service is held at a church or occasionally at a funeral home. The evening before the funeral there may be a brief prayer service.

Flowers can be sent to the church, the funeral home or graveside as a sign of condolence. In addition, memorial donations are acceptable. At the funeral, the casket may be open. Incense, repetitive singing, prayers and candles may also be included in the service. The funeral service does not require visitors to participate; they need only come and listen. The church may or may not have seating, attendees may be required to stand during the entire service. It is appropriate to wear dark colours, including black. Men wear long sleeves and long pants. Women should wear skirts below their knees as well as long-sleeve blouses. It is customary for women to cover their heads, but it is not always practised, Dress is more formal when the ceremony is conducted in a church rather than in a funeral home. Cremation is forbidden.

After the funeral there is a wake, where a meal is held in memory of the deceased, put on by the family in either a hall or at the family's home.

Memorial services are held in honour of the deceased. These are carried out nine days, forty days, three months, nine months, and one year after the person's death. Subsequently, memorial services are held each year on the day of the person's death, or the closest Sunday to it.

Protestant

There are a multitude of denominations within the Protestant faith. All revolve around the Christian theme that there is life after death.

Funeral services most commonly take place at a funeral home, although they may be held in a church. Mourners can visit the funeral home and pay their respects prior to the day of the funeral, usually within three days after death. The casket will probably be closed prior to the service.

It is appropriate to send flowers, cards and to make charitable donations in the name of the deceased. Although it is unnecessary for guests to dress in black or to cover their heads, it is expected that visitors dress respectfully. Dress is becoming more casual.

A Minister usually conducts the service; however, participation by family and friends is increasing. Visitors are not expected to participate, although some services allow for spontaneous eulogies to be given. The service may include sacred music, prayers, readings, a sermon, and benediction.

At the cemetery a crematorium, another shorter service, called the committal, is given. Afterwards, guests may be invited to a reception at the family's home, a community hall or the funeral home.

Sikh

Funerals usually take place within 48 hours of death and are usually held at a funeral home, not a temple. While men and women sit apart in a temple, this is not the case at a funeral home. A head covering is required for both sexes (a scarf is adequate for men and women.)

At the funeral services, passages from the Guru Granth Shaib (the Sikh holy book) are read and prayers are offered. Relatives and close friends are expected to recite scriptural hymns. The body of the deceased is then transported to a crematorium, where a similar service takes place.

Afterwards, everyone gathers at a temple, where more religious services are performed, followed by a meal. At the temple, shoes must be removed, a head covering is required, and men and women sit apart.

Sending flowers or a donation are both considered appropriate.

5 - 8 SERVICES AND PRODUCTS

5 - 8.1 Embalming

Embalming is the process used to temporarily preserve human remains, forestall decomposition, and to make the remains suitable for public display.

Modern embalming procedures start with the washing of the body with disinfectant and germicidal solutions. The embalmer then "sets the features" - a complicated process that involves closing the eyes and mouth and ensuring the facial features are natural and that they closely approximate how the deceased looked in life. Embalming chemicals are then injected into the arteries and body cavities.

Many funeral homes require embalming if you are planning a viewing or visitation. However, embalming generally is not necessary, or legally required, if the body is buried or cremated shortly after death. Many religious traditions, in fact, forbid embalming and demand that the deceased be buried within 24 hours of death. Choosing not to embalm a body can result in savings of hundreds of dollars.

A funeral provider:

- Cannot embalm the body without permission
- Must disclose in writing that embalming is not required by law (except in certain special cases)
- Must disclose in writing that certain disposition options, such as a direct cremation does not require embalming

- Must disclose in writing that some funeral arrangements, such as a funeral with a viewing, will make embalming a practical necessity (and, if so, a required purchase)

Attempts to preserve the body have a long history. As far back as the ancient Egyptians, people have used oils, herbs, and special body preparations to help preserve the bodies of their dead. And yet, no processes or products have yet been devised to preserve a body in the grave indefinitely. Regulations, as a result, prohibit funeral providers from suggesting that either embalming, or a casket or vault, will preserve the body of the deceased for an unlimited amount of time.

5 - 8.2 Caskets

A casket is often the single most expensive item purchased for a "traditional," full-service funeral. Caskets vary widely in style and price and are sold primarily for their visual appeal. Typically, they are constructed of metal, wood, fiberboard, fiberglass, or plastic. Although an average casket costs slightly more than $2,000, some mahogany, bronze or copper caskets sell for as much as $10,000.

As noted earlier, when visiting a funeral home or showroom the regulation provides that the funeral director provides you with a full list of the caskets available - along with descriptions and prices - before showing you the actual product. Industry studies have shown that the average casket shopper buys one of the first three caskets he sees - usually the "middle-priced" model.

It is, therefore, in the seller's best interest to start out by showing consumers the higher-end models. Consumers should always ask to see the lower-priced models on the price list—but they should not be surprised if these offerings are not prominently displayed.

Historically, the sale of caskets has been the purview of funeral homes. However, with increasing frequency, showrooms and websites operated by "third-party" dealers are now selling caskets. It is possible to purchase a casket from one of these dealers and have it shipped directly to the funeral home. Funeral homes must accept caskets bought elsewhere and they cannot charge a separate fee to cover handling them.

No matter where the casket is purchased, it is important to remember that it's' sole purpose is to provide a dignified way to move from the funeral home to burial or cremation. No casket, regardless of its qualities or cost, will preserve a body forever. Metal caskets, frequently described as "gasket," "protective," or "sealer" caskets, incorporate a rubber gasket or some other feature - designed to delay water penetration - into their design. Features of this nature do not help preserve the body indefinitely - they merely add to the cost. Metal caskets are made from rolled steel of varying gauges—the lower the gauge, the thicker the steel. They often include a warranty (for longevity).

Wooden caskets, on the other hand, generally do not have "gaskets" and do not have a warranty for longevity. They are usually made of either hardwood (such as mahogany, walnut, cherry, or oak) or softwood (often pine).

Pine caskets are a less expensive option, but funeral homes rarely display them.

Manufacturers of both wooden and metal caskets usually offer warranties on workmanship and materials.

The following indicates a range of the different types of caskets available - starting with the lowest cost:

- Plywood - with no interior
- Composite material – Cloth-covered fiberboard, raised flat top
- Wood Veneer – Taffeta interior
- Pecan Hardwood – Champagne sovereign velvet interior
- Cherry Hardwood – Champagne velvet interior
- Stainless Steel – Silver sovereign velvet interior
- Copper – Champagne sovereign velvet interior

Keep in mind that the caskets described above are but a small fraction of the options available. There are literally hundreds of different caskets to choose from.

5 - 8.3 Cremation

Many families, that opt to have their loved ones cremated, rent a casket from the funeral home for the visitation and funeral. This saves them the cost of buying a casket. Rental caskets include an outer shell and an inner removable liner.

Under Provincial regulations, funeral homes that offer direct cremations:

- Must make an unfinished wood box or other alternative container available for direct cremations
- Must disclose, in writing, the consumer's right to buy an unfinished wood box or an alternative container for a direct cremation
- May not indicate that local law requires the use of an ornamental casket

5 - 8.4 Burial Vaults or Grave Liners

Burial vaults or grave liners, also known as burial containers, are commonly used in traditional, full-service funerals. The vault or liner is placed in the ground before burial, and the casket is lowered into it at burial. The purpose is to prevent the ground from caving in as the casket deteriorates over time.

A grave liner is made of reinforced concrete and will satisfy any cemetery requirement. Grave liners cover only the top and sides of the casket. A burial vault is more substantial and expensive than a grave liner. It surrounds the casket in concrete or another material and is often sold with a warranty.

Provincial laws do not require a vault or liner, and funeral providers are prohibited from suggesting otherwise.

However, keep in mind that many cemeteries require some type of outer burial container to prevent the grave from sinking in the future.

Neither grave liners nor burial vaults are designed to prevent the eventual decomposition of human remains. It is illegal for funeral providers to claim that a vault will keep water, dirt, or other debris from penetrating into the casket.

Before showing a consumer any outer burial containers, a funeral provider is required to provide a list of prices and descriptions. It may prove less expensive to buy an outer burial container from a third-party dealer, than from a funeral home or cemetery. Prices should also be compared before selecting a model.

5 - 8.5 Cemetery Sites

When purchasing a cemetery plot, such things as the location of the cemetery and whether it meets any religious requirements should be considered. Other considerations include what, if any, restrictions the cemetery places on burial vaults purchased elsewhere, the type of monuments or memorials it allows, and whether flowers or other remembrances may be placed on graves.

Cost is another consideration. Cemetery plots can be expensive, especially in metropolitan areas. Most, but not all, cemeteries require that consumers purchase a grave liner, which will cost several hundred dollars. Note that there are charges—usually hundreds of dollars—to open a grave for interment, and additional charges to fill it in. Perpetual care on a cemetery plot sometimes is included in the purchase price, but it is important to clarify that detail beforehand. If it is not included, look for a separate endowment care fee for maintenance and grounds keeping.

Even if the cremated remains are to be interred in a mausoleum or columbarium, there will still be costs associated with the crypt (i.e., the space the urn occupies), opening and closing fees, and charges for endowment care and other services.

5 – 9 MEMORIALIZING THE DEAD

5 - 9.1 Death Notices and Obituaries

Most people are unaware of the distinction between a death notice and an obituary. The former is a paid listing that is composed by the family and submitted to a newspaper. The latter is a news story that is composed by the newspaper and which is usually only reserved for the most well-known citizens of a community.

Since families pay for death notices, they are free to say whatever they please about the deceased if it is appropriate in length and in good taste. A picture of the deceased may or may not be included. Most death notices follow a similar formula - covering pertinent information about the deceased (cause of death, dates, surviving family members), highlights of their life and career, information concerning the funeral plans, and their expectations with respect to expressions of sympathy (e.g., flowers, donations, etc.).

Most newspapers will only take information for death notices from a funeral director. If a family wishes to compose a death notice on their own, usually they will be required to submit it in person, along with a copy of the death certificate. This is meant to limit the unfortunate experience of false death reports.

Since obituaries are news stories, the family has little control over them. The newspaper decides whether to run an obituary, or not, and it often follows a formula with respect to what is and is not included. In some instances, certain unfortunate aspects of the deceased's life may be covered.

5 – 9.2 Visitation

The visitation or "viewing" is a time when friends and family can come and say their last farewells, commiserate and share recollections of the deceased's life. The body of the deceased - or his or her cremated remains - are almost always present at the visitation.

Years ago, bodies were kept at home and the life of the family continued around the deceased. Today it is much more common for the body to be at a funeral home - and this is normally where visitations occur. Even with cremations, visitations often take place at the funeral home.

Those who come to honour the deceased and say their last farewells will usually be expected to sign a guest book, approach the body if it is present, and to communicate their condolences to the immediate family.

Depending on tradition a visitation can cover the gamut from rigid and openly emotional to highly informal, relaxed and subdued. Usually visitors can count on being forgiven for a certain awkwardness initially. They will almost always be gratefully received by the bereaved. It is difficult to offend anyone if you are trying to express your concern and honour the deceased.

Family pictures, and other mementoes associated with the deceased are often displayed at the visitation.

5 – 9.3 Memorial Service

Unlike the visitation, which usually takes place before the funeral and interment, a memorial service is usually conducted afterward.

The body is usually not present during a memorial service.

Music and art are often an important part of memorializing the dead. Families might well want favourite music played and family pictures - and possibly other mementoes - displayed. Immediate family and others present will often make presentations to commemorate the deceased.

5 – 9.4 After Burial or Cremation

After a funeral, families often invite others to join them at home, or in a hall or restaurant, to talk, remember the dead, and share a sense of fellowship and community.

In some religious traditions, the family stays at home and receives visitors or says prayers for a substantial period. In some cases, survivors are expected to wear special clothes or to abstain from certain activities for a prescribed period. Since these mandates are uncommon and vary substantially, it is a good idea to inform others as to what is to be expected in the death notice or elsewhere (e.g., a handout distributed during the visitation, funeral, etc.).

5 - 10 COST

5 - 10.1 Basic Service Fee for the Funeral Director and Staff

Funeral regulations allow funeral providers to charge a basic service fee that customers cannot decline to pay. The basic service fee includes services that are common to all funerals, regardless of the specific arrangements made.

These services include funeral planning, securing the necessary permits, producing copies of the death certificate, preparing the remains, and co-ordinating arrangements with the cemetery, crematory, or other third parties. The fee does not include charges for optional services or merchandise. This basic service fee can vary substantially from funeral home to funeral home.

5 - 10.2 Charges for Other Services and Merchandise

Depending on the family's specific funeral plans certain optional goods and services will, of necessity, be required. These include transporting the remains, embalming, the use of the funeral home for the visitation or memorial service, hearse and limousine rental, caskets, etc.

5 - 10.3 Cash Advances

The funeral home - on the instructions of the deceased's family - will often arrange to purchase a variety of goods and services from outside vendors. This simplifies things for the family - since they do not need to contact these people or to pay individually for their services. The funeral home makes all the arrangements, advance cash to these outside vendors, and then adds the cost onto the bill it presents to the family.

Cash advances are made to such outside vendors as: florists, newspapers, pallbearers, officiating clergy, organists and soloists. Some funeral providers charge the family the actual cost of the items purchased, while others charge the actual cost plus a service fee.

5 - 10.4 Cost Estimates

The funeral provider must provide the people arranging the funeral with an itemized statement of the total cost of the funeral goods and services that have been selected. If the funeral provider is unable to provide a firm costing (because of some uncertainty with respect to, for example, the cash advances required), then he or she must provide a written "in good faith" estimate. The costs covered by the funeral provider must include not just his own fees - but also cemetery or crematory costs.

There are no specific regulations with respect to how the above information must be formatted or presented.

5 - 10.5 Why Are Funerals Expensive?

When compared to other major life cycle events, such as weddings, funerals are not actually that expensive. Wedding costs can be three or four times more than the average funeral. But since weddings are both happy events and discretionary, very few people complain about the cost.

A funeral home is a 24-hour, capital-intensive business, with elaborate facilities and equipment (i.e. Viewing rooms, chapels, limousines, hearses, etc.). Covering this overhead must be factored into the fees charged by the funeral home.

The fees paid must also include the work of the funeral director and his staff. These professionals must coordinate the entire process and ensure that matters are handled in a timely fashion, with both precision and care.

5 - 10.6 Sample Cost

The costs on the next page were taken from a Southern Ontario Funeral Home's 2018 general price list.

Table 5 – 2 Sample Funeral Costs

DESCRIPTION	COST
A - PROFESSIONAL & STAFF SERVICES	
Funeral Director's Professional Services: This charge includes, but is not limited to, consultation and assistance with the planning of the funeral service, co-ordination of external services, supplies, supervision, and direction of all arrangements pertaining to the funeral services and final disposition. These services are available on a 24-hour basis. Includes staff assistance in local removal from place of death, care and arrangement of flowers, receptionists, secretarial services, and maintenance of facilities.	$850.00
Documentation and Registration: Preparation and filing of the necessary documents and permits, including unlimited proof of death certificates.	$200.00
Embalmer's Professional Services: Except in certain special cases, law does not require embalming. However, the funeral home's policy is that embalming is necessary if arrangements include visitation or if we are asked to hold the remains of the deceased for more than 24 hours.	$480.00
Other Preparation: These services may include, when necessary, cosmetology, placing the body in the casket or container, special care of autopsied remains, sanitation and exterior disinfecting of the body when no embalming is authorized.	$150.00

B – FACILITIES AND STAFF	
Use of the Funeral Home:	
Use of the Funeral Home for Visitation Period – each day	$575.00
Use of the Funeral Home for the ceremony	$180.00
Daily Cost of Staff (This includes the visitation room and all facilities available, such as a coffee lounge, coatroom, washrooms, and parking).	$420.00
C – AUTOMOBILES	
Transfer of the Deceased	$425.00
Funeral Coach	$380.00
Lead Car	$115.00
Limousine for family	$325.00
Limousine for Pall Bearers	$325.00
Extra Limousine for Family	$325.00
(For any of the above vehicles, these charges apply to an 35-kilometer radius. Distances over this will be charged at $1.80 per kilometer).	

D – SUNDRY ITEMS	
Register Book	$75.00
Acknowledgement Cards	$75.00
In Memoriam Cards	$100.00

Table 5-3 Actual Funeral Costs from an Ontario Funeral Home

<table>
<tr><td colspan="2">Based on this price list, a typical funeral involving one day of visitation, use of the funeral home on the day of the funeral service, as well as automobile costs and sundries (but not including the casket, cemetery fees, disbursements, etc.) would cost:</td></tr>
<tr><td>Funeral Director's Professional Services</td><td>$850.00</td></tr>
<tr><td>Documentation and Registration</td><td>$200.00</td></tr>
<tr><td>Embalmer's Professional Services</td><td>$480.00</td></tr>
<tr><td>Other Preparation</td><td>$150.00</td></tr>
<tr><td>Use of the Funeral Home (Visitation)</td><td>$575.00</td></tr>
<tr><td>Use of the Funeral Home (Day of Service)</td><td>$180.00</td></tr>
<tr><td>Staff (two days at $420 per day)</td><td>$840.00</td></tr>
<tr><td>Transfer of Deceased</td><td>$425.00</td></tr>
<tr><td>Funeral Coach</td><td>$380.00</td></tr>
<tr><td>Limousine for Family</td><td>$325.00</td></tr>
<tr><td>Limousine for Pallbearers</td><td>$325.00</td></tr>
<tr><td>Register Book</td><td>$75.00</td></tr>
<tr><td>Acknowledgement Cards</td><td>$75.00</td></tr>
<tr><td>In Memoriam Cards</td><td>$100.00</td></tr>
<tr><td>**TOTAL**</td><td>**$4,980.00**</td></tr>
</table>

The above cost, however, does not take into consideration additional costs such as: caskets, urns, and vaults. The following costs were taken from the same small-town Ontario Funeral Home’s 2018 price list.

Table 5 – 4 Other Costs

CASKETS	
Cremation Container	$ 850.00
Cloth covered pressboard – crepe interior	$ 1,400.00
Wood veneer – crepe interior	$ 2,500.00
Solid Walnut – velvet interior	$ 9,700.00
Solid Maple – crepe interior	$ 3,850.00
Copper – velvet interior	$ 9,700.00
Steel (20 gauge) – crepe interior	$ 2,800.00
Rental Casket (with removable insert) - crepe interior	$ 1,600.00
Concrete Vault	$ 1,600.00

URNS	
Ceramic	$ 195.00
Bronze	$ 230.00
Wood	$ 155.00
Pewter	$ 360.00
Marble	$ 350.00
Urn Vault	$ 1,000.00

And even with the above factored into the equation, there is still more in the way of costs to consider. The Clergy honorarium ($200); the church fee ($100); the organist's fee ($125); the cost of additional music ($100); plus, flowers, death notices, catering, cemetery plots, memorial stones, etc.

Cemetery costs vary widely. A cemetery plot in a small town can go for as little as $500, while a standard single plot in a major city can run in excess of $10,000. Mount Pleasant cemetery in the heart of Toronto charges between $12,300 and $17,800 for a single plot.

The cost of a grave stone will vary based on its size – but prices generally range between $1,500 and $6,400.

In addition, cemeteries charge interment fees of between $900 and $1,900.

5 – 10.7 Cost Variations

As noted above, the cost of a funeral will vary significantly depending on where a person lives and on which funeral services provider is used. There are significant differences in cost between different jurisdictions.

When it comes to a traditional funeral, in 2017, Nova Scotia was the most expensive place to die (and Halifax was the most expensive Canadian city). In Nova Scotia the average traditional funeral costs $10,495 (including all funeral home costs, and such hardware as caskets and vaults). The cheapest place to die was Saskatchewan, where the average traditional funeral cost was about $7,775.

In order to manage costs, people should check what kind of funeral business they are dealing with. There are two corporate funeral companies operating in Canada – Service Corporation International [Branded as Dignity Memorial] and Arbor Memorial. Although not a rule, often the corporate funeral homes can be more expensive than family-owned funeral homes. In the funeral industry economies of scale do not always operate in the consumers' favour. It is strongly recommended that Canadians investigate prices from more than one funeral home.

When it comes to trying to establish average burial costs, a variety of variables must be considered. Things like type of casket, casket liner, vault, cemetery plot, grave marker, etc. In the case of a burial, embalming is an additional cost, plus dressing, a viewing, vehicles required, services of a celebrant and the list goes on. At a stressful time, all these questions and choices can be so daunting that the bereaved often are so overwhelmed, that the stock answer is "give her a good send-off." A "good send-off" in the case of a traditional burial can start at around $5,000 but can quite easily amount to a cost of $15,000.

As a very general guide a cremation is likely to cost a quarter of the cost of a burial. The average cost of a cremation also varies significantly. The most expensive place to be cremated is Saskatchewan with a cost of $2,401 on average. The cheapest place to be cremated is British Columbia (average cost, $1,917).

For anyone looking for the most economical funeral option, it is direct cremation. A low-cost cremation can be obtained in some areas of Quebec for as little $587, in Vancouver for $995 and in Toronto for $1,400.

5 - 11 PREPAYMENT

Approximately 600,000 Canadians have entered into contracts to prearrange their funerals and prepay some or all the expenses involved. The two most common forms of prepayment involve either the use of a trust or a funeral insurance product.

5 - 11.1 Trusts

In the case of trusts, once the funeral has been planned, the necessary payment to cover it is invested in a trust (for the benefit of the person whose funeral is being planned). The fact that the funds invested are not held by the funeral home provides considerable security for the consumer. If the funeral home goes out of business, the funds held in the trust are fully protected and they are easily transferable. This transferability is also helpful in situations where the consumer moves.

Payments into the trust can typically be made on either a lump sum or an instalment basis and the funds provided are generally invested quite conservatively.

Most funeral operators will guarantee that the funds in the trust along with any earnings will be enough to cover the cost of the selected goods and services in the future.

This provides the consumer with inflation protection - no matter how significantly costs may escalate, the funds in the trust will be enough to fully fund the funeral arrangements planned. In situations where the money invested in the trust is more than what is needed to fund the funeral goods and services selected, a refund is usually provided.

The advantages of using a trust to pre-fund funeral arrangements include:

- In most cases, funeral costs are guaranteed, at today's prices
- The money deposited is safe (i.e., held in trust for the benefit of the consumer and invested conservatively)
- The funds held in trust are easily transferred
- Payments can be made in a lump sum or in monthly instalments
- Most or all the money will be refunded if the consumer changes his or her mind
- Any growth in the trust fund is tax sheltered

Since the regulations concerning prepayments differ from province to province, it is always a good idea for the consumer to ask a lot of questions about the nature of these trust arrangements, with attention paid to such things as: refunds, transferability, guarantees, etc.

5 - 11.2 Funeral Insurance

The cost of a funeral may also be pre-funded through funeral insurance. At advanced ages, the cost of the insurance will be equal to the full cost of the funeral goods and services chosen. At younger ages, a discount is usually applied. The contract is generally taken out in the name of the consumer with the funeral home named as beneficiary. This, of course, ensures that the consumer has full control over the policy. He or she can change the beneficiary - if necessary - at any time.

It also ensures that the funds are safe in the event of the collapse of the funeral home.

Premiums may be paid as a lump sum or in instalments over a period. Since a medical is usually not required, there are limits on the death benefit payable in early years (except in the case of accidental death). A popular Canadian plan restricts the death benefit to premiums paid plus 20% during the first year; premiums paid plus 30% during the second year; and the full death benefit thereafter.

As with trust accounts, funeral insurance arranged through a funeral home is usually guaranteed to be enough to cover the future cost of the funeral.

Funeral insurance offers some advantages - as well as certain disadvantages - when compared to the use of trusts. Among the advances: the full death benefit is usually available within two years of purchase - even on instalment plans; and funds are easily reassigned without penalty (funeral homes can keep an administration fee, of up to 20% of principal and interest, when trust accounts are altered). Among the disadvantages of funeral insurance: the insured may find it very difficult to negotiate a refund of the premiums paid.

A final note - anyone who decides to prearrange and prepay for funeral services should make their family aware of these arrangements and ensure that the pertinent documents are easily accessible. If family members do not know that some or all the costs of a funeral have been prepaid, they could end up paying - a second time - for the same arrangements.

5 - 12 FUNERAL FINANCIAL ASSISTANCE

Funerals are among the most expensive major purchases that most consumers will ever make. Most funeral directors will make every effort to ensure that the selections made are appropriate and well within the client's financial means.

Fortunately, financial assistance is available from a variety of sources.

5 - 12.1 Canada Pension Plan

Anyone, who has paid at least one premium into the Canada Pension Plan, qualifies for a Canada Pension Plan death benefit. This death benefit is equal to six times the monthly pension benefit they would normally be entitled to at age 65, up to a maximum of $2,500. Most Canadians qualify for a benefit at or close to the maximum.

5 - 12.2 Union or Employer Pension Funds

Death benefits and Accidental Death and Dismemberment benefits are widely available to members of a broad cross section of different unions.

In some cases, the benefits are quite substantial. Employer Pension and Benefit Programs also, often, include some death benefit provisions.

5 - 12.3 Fraternal Orders and Professional Groups

A variety of fraternal and profession organizations offer death benefits for their membership. A funeral director should be able to assist in determining what benefits may be available and in the application process.

5 - 12.4 Worker's Compensation

A Worker's Compensation death benefit is available to workers whose death is work related (i.e., it either occurred at work or is directly related to the deceased's employment). The benefits available vary from province to province, but a local funeral director should be well versed in the nature of the benefit available and the application process.

5 - 12.5 Last Post Fund

The Canadian Government has traditionally assumed responsibility for the burial of members of the Canadian Armed Forces who died during battle or who died as a result of war-related injuries. In the years following the end of the Second World War and the Korean War, benefits were expanded to veterans who died without the financial means to provide for a dignified funeral and burial.

Funerals for: veterans who died as a result of wartime injury (or a condition related to military service); and indigent veterans, are arranged by a non-profit organization - The Last Post Fund Corporation - on behalf of Veterans Affairs Canada.

The Last Post Fund covers the cost of:

- The services of a funeral director (of the family's choice, where possible)
- A solid wood casket
- Some transportation costs
- Cremation, including an urn
- Some costs associated with purchasing a cemetery plot; grave opening and closing; a grave liner, if required by cemetery regulations; and an inscribed grave marker (to Last Post Fund standards)

The maximum amount of compensation available through the Last Post Fund is $3,600, plus applicable taxes. However, The Last Post Fund - as well as other government programs of this nature - are currently under review and it is likely that they will become more generous and flexible at some point in the immediate future.

5 - 12.6 Other Policies

Life, health, and accident policies - even credit cards - should be examined for benefits. Sometimes, medical benefits of automobile insurance policies can be applied to funeral expenses. Financial advisors, insurance agents and funeral directors should all be able to assist in filing for benefits of this nature.

5 - 13 POST FUNERAL

A funeral is the formal ceremonial process that concludes a life. It affords us some time to reflect on the deceased, grieve the loss and honour their memory. So much attention is focused on it, that we often forget that in the weeks and months that follow the funeral there is a lot of work that needs to be done and many adjustments to be made.

5 - 13.1 Disposing of Personal Items

In concluding the affairs of a deceased person, there are always questions about what to do with items such as medical aids, clothing, linen, and furniture. There are practical ways of disposing of these items through a variety of charitable groups. It is often comforting for those who have lost a loved one, to make donations for the benefit of others in need.

The Lions Club, under their Lions Recycle for Sight program, collects more than 20 million pairs of eyeglasses each year and forwards them on to Third World countries. Hearing aids may be donated to the Canadian hearing Society, an organization that collects, refurbishes and then distributes them to needy Canadians. The Red Cross accepts wheelchairs and distributes them to the disabled.

New and sealed bandages, syringes, topical medications, and other supplies may be donated to the Victorian Order of Nurses, Canadian Cancer Society or the Red Cross.

Clean used clothing and linen in good repair, as well as furniture, can be donated to a variety of different charities - among them: Goodwill, The Salvation Army, women's shelters and drop in centres for the homeless. Most of these charities will arrange for the pick-up of household items (all the family must do is ensure that they are boxed or bagged and appropriately labelled).

The deceased's prescription medications - whether opened or not - should be returned to the pharmacy or disposed of at home. Another person should never use these products.

5 - 13.2 Support Services

It can take weeks, months and in some cases even years to fully deal with the emotional impact of the death of a loved one. Life does not necessarily get back to normal immediately after the funeral reception. Fortunately, there are a variety of support services available to people coping with death, grief, loss, and separation. These agencies can either offer direct support, or they can put grieving families in touch with qualified bereavement counselors.

Support is available from all the following:

- Canadian Mental Health Association
- Compassionate Friends
- Family Service Centres
- Hospices
- Police Departments
- The Red Cross
- Regional Hospital Centres
- Victorian Order of Nurses

Grieving family members should also be encouraged to maintain contact with their physician and clergy or spiritual advisors.

5 - 13.3 Family and Friends

The weeks and months after the funeral can often be the most trying time for those left behind. This period can be particularly difficult on an elder who has just lost their spouse. The following material offers eight tips with respect to what family and friends can do to help elderly surviving spouses cope.

One: be accepting and supportive of the new person the elder becomes in the wake of this devastating loss. Support him or her in new ventures and new friendships.

Two: let the elder decide when and how to dispose of the deceased spouse's clothing and personal items. Some may not be ready to do this right away.

Others may want to get it over with almost as soon as they get home from the funeral.

Three: let family traditions change and evolve to fit the new family structure. Do not force things that do not work without the deceased, or that are exceptionally painful in his or her absence.

Four: help the elder to become independent. Teach him or her something new that the deceased used to do, rather than just doing it for them.

This could be anything from balancing the chequebook, to maintaining the car, to cooking dinner.

Five: encourage the elder to delay making any major decisions, such as selling a home or moving to a new part of the country—for at least one year after the death.

Six: in the emotionally difficult time after the death of a spouse, elders are often tempted to loan money to others. Encourage them to resist this urge - at least until they have a better understanding of their new financial circumstances.

Seven: talk about the deceased. Talking about the deceased keeps the memories alive and helps in the healing process.

Eight: call the elder frequently, and make sure they feel comfortable calling you more often. This is particularly important for the elder's children. He or she may become very dependent on them for communication and companionship - especially in the short term.

5 - 14 CLOSING ADVICE

Much of the preceding material focuses on helping people to make informed decisions when it comes to funeral planning. The following summarizes a few of the key points previously covered:

- Shop around in advance - compare prices from at least two funeral homes. Remember that you can supply your own casket or urn.
- Ask for a price list - the law requires funeral homes to give you written price lists for products and services.
- Resist pressure - take your time and resist the pressure to buy goods and services that are not wanted or needed.
- Avoid emotional overspending - it is not necessary to have a fancy casket or the most elaborate funeral to properly honour a loved one.
- Recognize your rights - laws regarding funerals and burials vary from province to province. It is a smart move to know which goods or services the law requires you to purchase and which are optional.
- Apply smart shopping techniques - use the same cautious decision-making that you use for other major purchases. You can cut costs by limiting the viewing to one day or one hour before the funeral, and by dressing your loved one in a favourite outfit instead of costly burial clothing.

5 - 15 FUNERAL CHECKLIST

The following checklist is a helpful tool that can be used when planning - or pre-planning - for funeral arrangements. It also provides a great summary of many of the topics that have been covered in this chapter.

Table 5 - 5 Funeral Checklist

Personal Information

- Full legal name
- Residence
- Date and place of birth
- Citizenship
- Personal Health number
- Social Insurance number
- Length of time in province
- Occupation / Business or industry
- Marital status / Spouse's full name
- Father's name & birthplace
- Mother's maiden name & birthplace
- Next of kin / Executor's full name
- Next of kin's address /relationship
- Doctor’s name and address

Personal History

- Elementary school attended
- High school attended
- University attended
- Military record
- Family & professional history
- Offices or positions held
- Accomplishments, personal & professional
- Citations
- Hobbies, activities, and interests
- Charities & other special requests

Service Choices

- Choose a funeral home
- Set time & date of service
- Choose location of service
- Apply for burial permit
- Apply for death certificates
- Choose burial or cremation
- Request preparation and embalming
- Choose a family viewing or visitation
- Decide if the jewelry is to remain or to be returned
- Supply clothing for the deceased
- Select photographs to be displayed
- Select musical selections, hymns & solos
- Select scripture or literature
- Compose & submit obituary
- Choose the charity to direct donations to
- Religious or fraternal items
- Arrange location & food for the reception

People to Contact

- Extended family & friends
- Doctor (G.P. Or Specialist)
- Accountant, Lawyer
- Employer
- Insurance agent
- Creditors
- Financial Advisor / banker
- Clubs, unions & organizations
- Bereavement counselor if needed
- Canada Pension Plan / O.A.S.
- Dept. of Veterans' Affairs
- Canada Post - Change of Address

Services to Pay For

- Funeral Service
- Cemetery plot, perpetual care & interment fees
- Grave Memorial, Inscription & Installation
- Service participant
- Provincial documents
- Flowers / Food / Catering for the reception
- Ambulance
- Newspapers

Specific Selections

- Select casket or Cremation Container
- Select burial vault or cremation urn
- Choose cemetery / Select burial or cremation plot
- Decide whether above or below ground
- Select memorial grave marker & inscription
- Select memorial register
- Select memorial folders & acknowledgement cards
- Choose floral arrangement

Transportation Selections

- Ambulance transfer from place of death
- Funeral coach
- Clergy car
- Family limousine
- Pallbearer limousine
- Flower car

Funeral Participants

- Clergy or officiate
- Organist or other musical participants
- Pallbearers
- Family or friend to perform eulogy
- Family or friend who will read scripture or literature

Documents to Locate

- Will
- Deed to cemetery plot
- Birth certificate
- Marriage certificate
- Citizenship papers
- Insurance policies
- Bank documents
- Title to property
- Vehicle ownership
- Revenue Canada tax returns
- Military discharge papers

5 - 16 CONCLUSION

The loss of a loved one - particularly a spouse - creates a wide variety of challenges (emotional, financial, social) for most Canadian elders. Making a major financial decision concerning funeral plans, during this turmoil, merely compounds the problem.

There is a strong argument in favour of funeral pre-planning as a result. But in the absence of any pre-planning, it certainly cannot hurt to have a solid understanding of funeral home practices, services and costs. This chapter was designed to help provide a lot of this background information. Funerals are a billion dollar a year industry in Canada and - with the aging of the baby boomers - it is a business that is poised to grow significantly.

A little knowledge can go a long way in ensuring that the funeral plans made for a loved one are meaningful, appropriate, and cost effective. The information in this chapter can be used to help elders at what may be their greatest time of need.

5 - 17 REFERENCES

Andrew L Hodges Funeral Home, General Price List, 2014

Canadian Funerals Online, Do It Yourself Funeral Care, 2013

Everest Survey, 2013

Funeral Service Association of Canada

A Guide to Funeral Customs in Canada, Sids Canada, 2014

Handbook for Mortals: Guidance for People Facing Serious Illness - By Joanne Lynn, M.D. and Joan Harrold, M.D.

Provincial Government Funeral Handbooks

Final Purchase Growing Demand: The Canadian Funeral Services Industry, March 2001

Statistics Canada

Chapter 6

Bereavement - Grief, Mourning & the Healing Process

---

6 – 1 KEY OBJECTIVE OF THIS CHAPTER

To a large degree, loss and aging go hand in hand - they are both an inevitable part of the human life cycle. As we age, we lose our health, much of our previous potential, and many of our friends and family - and bereavement and grief are a natural by-product of this experience.

The following chapter is designed to help you to understand bereavement - which, in turn, will help you to both cope with loss and assist others who are facing the challenges that it presents.

6 - 1.1 How Will This Objective Be Achieved?

“In a world that is often grief avoidant, learn that grief is not about a broken brain, it is about a broken heart and loss of a relationship.” Ms. Laurie Martin - Author of Life Interrupted – Greater Success by Managing Life’s Toughest Moments.

We will take a close look at bereavement and the grieving process. We will look at the five dimensions of grief; types of grief; physical manifestations of grief; and factors that trigger and influence the way it develops.

In addition, we will examine some of the strategies that can be employed to help elders, and others, cope effectively with loss - particularly during such difficult times as holidays, birthdays and other anniversaries. We will also look at some of the resources that can be accessed in situations where grief becomes overwhelming and unmanageable.

There is no right or wrong way to manage loss - no magic formula, no short cut, and no easy way out. Grief is full of twists and turns, roadblocks and dead ends. In the words of Stephanie Ericsson, author of *Companion Through the Darkness*:

“Grief will make a new person out of you, if it doesn't kill you in the making."

Do not let grief own you. We need to learn about grief and loss in order to help ourselves and help our clients. We should not teach our knowledge but walk alongside of our clients and loved ones when they are most vulnerable.

6 – 2 INTRODUCTION

Loss is an essential part of human experience. Every era, every race, every culture, and every human are eventually forced to come to terms with loss and the grief that almost always accompanies it. Every individual's experience of loss - and the pain and grief it inflicts - is unique. Everyone struggles to find ways to cope, to endure, to continue with life despite how they feel.

For most, the grieving process eventually leads to a form of reconciliation. They come to realize that loss is linked to personal growth. Their experience of loss offers them a new perspective and gives them a new appreciation of life.

Others remind themselves that loss is inextricably linked to everything that is good in life. We are vulnerable to grief precisely because we love, we care, and we value someone or something beyond ourselves.

In the end, saying "goodbye" can be both healthy and productive, signifying the end of what once was. It offers a sense of closure and better prepares us for what is to come.

A sense of loss can be triggered by a wide variety of different circumstances. Accepting a new job, moving to a new city, new (or altered) relationships, or a change in health, or moving into a retirement or long-term care facility can all produce a sense of loss. Most of life's major events involve both a beginning and an end, and it is perfectly natural that "the end" should produce a sense of loss.

- Everyone has, or will, experience the loss of something or someone, at sometime
- Every change - whether good or bad - results in a loss
- At some point in life, everyone experiences the death of someone they love

6 - 2.1 Death

Much of this chapter will focus on the loss associated with the death of a loved one - whether it is a close friend, a family member, an associate or a spouse. Death is, of course, inevitable: the normal and expected culmination of a life - the destination on every human being's journey.

Surprisingly, however, death is not actually the greatest loss we experience in life. The greatest loss is what dies inside people when they experience the death of a loved one.

6 – 3 GRIEF

Grief is all the thoughts and feelings on the inside of us. It can cause an overwhelming feeling of sorrow, pain, regret, and sadness. You feel as if your heart is broken—that nothing will ever be the same—that happiness will never be possible again. At times, we may even come to believe that death would be a release - and a relief.

Grief is a universal human emotion—*and* one of the most isolating. The entire world may love a lover, but few of us know how to deal with people who are in grief. Most of us struggle to manage our own grief and we are equally ill equipped to help others who are grieving.

Each person grieves in his or her own way, and according to his or her own needs. There is no formula for grief, and no way around it. As with other emotions - like joy, anger and fear - grief is just simply there. You cannot wish grief away and it cannot be ignored. Grieving is the mark of having been close to another person. The only way to avoid grieving is to avoid having loved.

Grief, like death, is something that many people have a difficult time discussing. Unlike other emotions that most of us have grown comfortable describing, there are no ready words, no clichéd expressions, to help explain grief. When we are happy, we might say we are *on top of the world*, *flying high, or on cloud nine*. When we are angry, expressions like, we have *had it up to here*, we are *seeing red, or we have blown our top* might be used. There are not any equivalent expressions to help us express grief.

And while grief may not be easily expressed outwardly, the emotions it produces can be remarkably strong. We can feel anger, loneliness, depression, guilt, sorrow, fear, and anxiety. Often, we will swing wildly from one emotion to the next, overwhelmed by the strength of the feeling and unable to make sense of it.

Grief is experiences we will all visit, and it is helpful to know what it is like there, how others have survived the journey and which road maps will help along the way. Much can also be learned from the setbacks experienced by others.

6 - 3.1 Circumstances That Can Cause Grief:

- Death of a spouse or child
- Death of a close relative or friend
- Death of a pet
- Divorce
- Loss of future
- Losing one’s independence
- Occupational change

- Change in health
- Financial setback
- Child leaving home

6 - 3.2 Grief And the Loss of a Loved One

Many assume that grief is associated only with the loss of a loved one; however, this is very often not the case, but those suffering grief are often told to “snap out of it.” Grief is, quite simply put, a response to loss. The loss can be of something tangible or intangible. It helps to recognize that disappointments, abuse, recognizing one’s limitations, losing a job, losing a sense of future, or so many other things can elicit a grief response. People suffering a loss need time to grieve, and such time depends upon how important the loss was.

Almost everyone has experienced the loss of a loved one. Sometimes death occurs suddenly, as the result of an accident, while at other times it takes place over a long period due to a chronic illness. Either way, there are few things more emotionally painful than losing a loved one. Elders tend to experience grief and loss more often and more severely than younger adults.

When a death occurs, there can be an array of emotions. They may suddenly feel helpless and overwhelmed. Grieving the loss of a loved one is a painful process, but it is the mind and body’s way of accepting the loss. Venting and emotional outbursts are a medicinal release that ultimately may assist in helping the bereaved to move forward one day at a time.

Trying to cover-up or ignore their emotions can be counterproductive and lead to greater pain and suffering over the long term. Approaches designed to avoid or "mask" one's emotions can include indulging in needless activities to the point of exhaustion, using alcohol or other drugs to self-medicate to attempt feeling better, and acting resentful toward people who are trying to help. These behaviours are attempts to deny reality during a period when it is necessary to face the truth, address the painful emotions experienced, and move forward.

When it comes to unfinished matters and lose ends that the deceased may have left behind, the bereaved may be the best person to talk to. By supporting them and allowing them to talk, gives them a sense of validation of what they are feeling is real and okay. It is easy for the bereaved to shy away from conversations about their loss.

There are a variety of people in every community who are more than willing to help. In addition to family and friends, members of the clergy, workers at crisis management centers, and other support groups are available to offer both encouragement and support. If social and community support systems are unable to meet the needs of the bereaved, then a visit to the family doctor may be in order.

Doing so may be particularly appropriate in situations where the grieving process appears to be extending long periods of sleeplessness or anxiety, taking a heavy toll on normal social interaction and daily activities. A physician can help on a multitude of fronts: new medications, additional tests, counseling, or referral to a specialist.

In addition, the bereaved should allow themselves some quiet time, to reflect, to contemplate the future and make plans to move forward. It will take time for them to move from who they were before the loss, on to who they will become after the grieving process has ended.

6 - 3.3 Unaddressed Grief

According to grief experts, when grief is not expressed, or unaddressed - for a prolonged period, it can lead to several serious problems, including:

- Depression and anxiety
- Heightened levels of stress
- Emotional problems
- Behavioral changes, or behavioral manifestations
- A deterioration in physical health
- An inability to complete routine tasks

6 – 4 THE MANIFESTATIONS OF GRIEF

6 - 4.1 Physical Manifestations

In response to the shock to one's system - caused by the news of a death - the human body releases chemicals - among them adrenaline. The chemicals released are designed to help the individual to think clearly, to remain alert, and to cope effectively with the emotional pain that has been triggered.

Other physical manifestations of grief include an inability to sleep, a lack of motivation, restlessness, forgetfulness, difficulty sitting still, an inability to concentrate, an inability to make decisions, loss of appetite, stomach upset, and sometimes even chest pain (which should be checked by a doctor). In addition, the person grieving may experience dry mouth, a lump in the throat and weakness/lack of energy.

Sometimes people can feel emotionally numb and they carry out activities as if they were on some form of “automatic pilot." They are physically present, but emotionally detached.

6 - 4.2 Emotional-Intellectual Stages (Dimensions)

There is a myth that grief is predictable and that it follows an orderly progression. Stage-like thinking about both dying and grief has been appealing to many people. Somehow the "dimensions of grief" have helped people make sense out of an experience that is not as orderly and predictable as we would like it to be. If only it were so simple! The concept of "dimensions" was popularized in 1969 with the publication of Elizabeth Kubler-Ross' landmark text On Death and Dying. Kubler-Ross never intended for people to literally interpret her five "dimensions of dying." However, many people have done just that, not only with the process of dying, but with the processes of bereavement, grief, and mourning as well. One such consequence is when people around the grieving person believe that he or she should be in "stage 2" or "stage 4" by now. Nothing could be further from the truth. Each person's grief is uniquely his or her own. It is neither predictable nor orderly. Nor can its different dimensions be so easily categorized. We only get ourselves in trouble when we try to prescribe what the grief and mourning experiences of others should be—or when we try to fit our own grief into neat little boxes.

Several decades ago, Elisabeth Kubler-Ross described what have come to be known as the five stages of grief - the five emotional-intellectual responses people have as they come to terms with a loss. They are denial, anger, bargaining, depression and acceptance.

Unfortunately, there has been a great deal of confusion with respect to how these different stages of grief manifest themselves. Many people mistakenly assume that they move forward in an orderly and linear fashion from one stage to the next. This is not the case.

NOTE: The following information is to be used as a learning guide only for awareness of what grief looks like. It is not our job to fix or teach our clients. The important learning is to be empathetic, patient and have a good listening ear for the bereaved.

Grief is not linear or predictable. Grief runs on its' own timetable and it follows its' own circuitous route. Different people will grieve differently, and a different amount of time is needed for each person experiencing their loss. Grief is extremely personal due to our own personality, how we perceive our world and the intensity of the relationship or circumstances.

Some people may experience all five of the following dimensions, while others may only experience two or three. There are no patterns. People move from one place of thinking and feeling to another, then back again, depending on their specific life circumstances and their own unique background.

For some people new losses may trigger old grief. Sometimes even an innocuous occurrence can release painful memories. One man, for example, described bursting into tears on a busy street when a passer-by tipped his hat - because it reminded him of his own late father.

6 - 4.3 Denial

"It can't be happening."

When a person is in denial, he or she often displays rather odd behaviour - particularly considering the circumstances. It is often difficult for those around the person to understand or accept how he or she is reacting. Individuals who are in denial tend to:

- Focus almost exclusively on the future
- Dodge conversations concerning the source of their bereavement
- Avoid family and friends (because they may confront them with the truth)
- Refuse to return phone calls

If a person is not accepting the loss, also called denial, individuals may tend to fantasize - to reject the truth and imagine that everything will be okay (e.g., "when I wake up, everything will be back to normal"). They often express a desperate need for reassurance on this front.

The family and friends of someone who is experiencing denial should keep in mind that denial acts as a buffer against the shock experienced by individuals who are confronted with a loss. Denial - and self-imposed isolation - can help individuals cope with traumatic news.

Family and friends should, therefore, give the bereaved some space and resist the temptation to force them to face up to reality. Pushing a person in this direction too soon is both unhelpful and unfair.

In order to support someone who is experiencing denial it is best to:

- Be non-judgmental
- Avoid taking anything personally
- Be a good listener - whenever they are ready to talk

6 - 4.4 Anger

"Why me? It's not fair."

Anger usually manifests itself when the bereaved person feels helpless, powerless and abandoned. Not everyone will feel anger.

If a person does feel anger, they may start to engage in a "blame game" - blaming themselves, blaming the person who has died, or blaming others for the loss. They may also start to vent at the injustice of it all and direct their anger at a higher power or at life in general. Convenient scapegoats are identified and the bereaved may.

- Blame the doctor, or the hospital, or the caregivers for "messing up"

- Dispute the prognosis and test results

Anger and guilt often go hand in hand. After each outburst, some guilt - at having been so negative - may surface. Feelings of this nature are quite natural and should be accepted as part of the process - a process that will eventually lead to some resolution.

6 - 4.5 Bargaining

"Please, I promise I'll be a better person if …"

The bereaved is finding a way to strike a deal - often willing to go to extreme measures - in order to make the loss disappear. They may become preoccupied with the things that could have been done to prevent the loss. They will desperately look elsewhere, and anywhere, for answers.

6 - 4.6 Depression

"I'm so sad. There's no point in bothering with anything."

After recognizing the true extent of the loss, some individuals may experience feelings of depression.

Sleep and appetite disturbance, lack of energy and concentration, and spells of uncontrollable crying, sobbing and weeping may overwhelm the bereaved.

Feelings of loneliness, emptiness, isolation, and self-pity can also surface during this phase. The bereaved may also lose faith and trust in life, in other human beings and with God.

6 - 4.7 Acceptance

"It's going to be okay. I'm ready for whatever comes."

With acceptance, the bereaved reaches a level of awareness and understanding with respect to the nature of the loss. This awareness allows them to do a better job of:

- Thinking rationally
- Verbalizing their loss
- Accepting the adjustments of change
- Adapting their lives to fit the new reality

Healing starts to take place as soon as the loss becomes integrated into the individual's set of life experiences.

The process through which a bereaved individual ultimately comes to terms with loss is often described by grief professionals using the acronym T.E.A.R.

T. - To accept the reality of the loss

E. - Experience the pain of the loss

A. - Adjust to the new environment without the lost person or object

R. - Reinvest in the new reality

6 – 5 COPING MECHANISMS

Whether an individual copes with a significant loss or death in a positive and constructive rather than in a negative or destructive manner depends on the types of coping mechanisms used and the quality of support being given.

There are two major psychological responses by individuals when adjusting to loss: the use of coping mechanisms; and emotional reactions. If we wish to help someone in a time of sorrow, we need to understand both.

6 – 5.1 Coping Mechanisms

Coping mechanisms operate to psychologically protect individuals and are used to reduce the level of anxiety they feel at a given moment. This allows them to better adjust to the loss and begin the grieving and healing process. The following describes the three main coping mechanisms:

Disbelief or Denial

This response reduces anxiety by allowing individuals to limit their awareness about the reality of what has happened until the pain can be let in more slowly. Everything inside shouts "No"! and the mind struggles to escape. Unable to tolerate the pain that would emerge if reality were faced, the individual experiences "emotional anesthesia".

Numbness and confusion are often predominant responses. Sighing and crying can be readily observed. Others cannot cry and may withdraw. This stage is relinquished more easily if people will listen to the bereaved person and help them express their whole range of feelings. Listening to feelings without giving advice is the best helping strategy.

Disorganization and Dependence

Characterized by a period of confusion in which the grieving person may feel out of touch with the ordinary proceedings of life. They may exhibit very dependent behavior and a time-orientation that focuses solely on the present.

They may become quite demanding, asking others to do things they normally can do themselves. Some of their talk and actions may seem foolish and out of character to others.

Intellectualization

A coping mechanism in which the grieving person attempts to master the loss by gathering a great deal of knowledge and information and analyzing in detail the situations leading to the loss. They may find out the most intricate medical data of a fatal disease, for example. Or they may plan in detail what will happen after the loss occurs. Individuals may rationalize the loss by saying “He’s better off in the long run,” or “She suffered so much.” This allows the individual to remain emotionally detached and to become an “observer” of the situation. If it remains within reasonable bounds, intellectualization can give the individual and family members a greater sense of control.

6 – 5.2 Emotional Reactions

Emotional responses coexist with coping mechanisms, but they do not necessarily protect the person from the trauma of loss. They are means for the individual to express emotions and feelings associated with the loss.

Friends can help by listening empathetically and resisting the temptation to return anger with anger or becoming defensive if they make accusations. Unexpressed anger may be turned inward and may be replaced by silent bitterness, indifference, apathy, aggression, and ultimately, depression.

Guilt feelings are frequently a part of the grief process. These feelings become focused as the individual searches for the cause of the loss thinking thoughts like these:

- “What did I do wrong?”
- “Could I have done anything differently?”
- “If only I hadn’t _____.”
- “If only I would have _____.”

When you live with someone for any length of time, you will say things you may regret. When that person dies, you suddenly realize all the things you wanted to say and did not. You remember words you wish you had not said or actions you wish you had not taken. It is human to feel guilty and to want another chance to erase neglect or failure. If the individual openly expresses guilt, it is better to encourage talking about it rather than clamming up. Saying “No, you’re not to blame” does not really help either. A caring person will encourage the full expression of feelings rather than blocking them, which would make the person feel even guiltier.

Shame occurs when a person is in a situation that is incompatible with the image that one wishes others to have. Shame, guilt, anger and regret often intertwine and are overlapping.

A farmer who involuntarily leaves the farm may believe that this reveals an intrinsic weakness or unworthiness in himself. When friends and family try to be encouraging and reduce guilt, it may undermine one's sense of dignity and self-esteem. Accepting the individual as an "OK" person and being there when needed is true friendship.

Loneliness and depression are considered the most painful processes. When a loved one is removed from their lives, people often are overcome by feelings of utter depression and isolation. Gradually the finality of the loss sinks in—an empty chair near the TV, an unused pillow, a family photo, a missing phone call. Sadness and depression follow, and self-pity is frequent.

Problems which are manageable when shared with a partner become magnified when faced alone. Sometimes an individual may search for a quick replacement. However, healing and recovery are more likely achieved if the bereaved person completes the grieving process before seeking a new partner or making any new lasting commitments. Delaying major decisions allows people to see new perspectives; to make decisions that can be more easily lived with during the years ahead.

Relief and reconciliation - feelings of relief are difficult to admit and acknowledge openly. Relief is so intermingled with our sense of loss that we cannot see it isolated enough to take it for what it is—a normal, human response. A feeling of relief does not imply any criticism for the lost relationship. There is an overlap between relief and reconciliation—in fact, feelings of relief may signal reconciliation and acceptance. As the individual brings acceptance of their loss, and as hope softens the intense feelings of loss, a new life begins. The person reaches out and makes constructive efforts to rebuild by responding more readily to phone calls, attending meetings, and seeing social gatherings as opportunities.

6 – 6 COMPLICATED GRIEF

Complicated, or unresolved, grief is characterized by symptoms that persist over an extended period, severely interfering with normal activities and which are extremely intense in nature (for example leading to suicidal thoughts or actions).

During the first few months after a loss many of the signs and reactions of normal grief are like those experienced in complicated grief. Normal grief, however, tends to fade after six months (depending on how much trauma was experienced with the loss).

With complicated grief, the reactions often worsen with the passage of time and they can linger on for years. Complicated grief is akin to being in a heightened, chronic state of mourning.

The signs and reactions of complicated grief can include:

- Extreme focus on the loss
- Intense longing or pining for the deceased

- A complete inability to accept the death
- Numbness and detachment
- Preoccupation with sorrow
- Bitterness
- Significant guilt
- Delusions
- Slower response times
- Extreme weight loss
- Inability to enjoy anything life has to offer
- Deep depression and sadness
- Inability to move on
- Difficulty carrying out normal activities
- Withdrawal
- Irritability and agitation
- Lack of trust in others

The risk factors that can lead to complicated grief include: the suicide of a loved one; a weak support system; few close friends; and the closeness of the relationship the survivor had with the deceased. Given the severe nature of complicated grief, the bereaved may often require some combination of medication and professional intervention prescribed by a family physician or psychiatrist.

Some of the more common forms of complicated, unresolved, abnormal grief are described below.

6 - 6.1 Chronic Grief

Chronic grief occurs when a person's grief fails to come to some finality or acceptance of their loss. Day after day, month after month, the individual's grief is as fresh as the day the loss occurred. Often the survivor will hold, touch or cling to a object that is associated with the deceased. Clinging to the past often becomes ritualized. One widow, for example, started every morning by opening her closet and smelling her deceased husband's favourite shirt. The bereaved can become stuck in the process and the routine - unable or unwilling to break free from it.

6 - 6.2 Delayed Grief

Delayed grief is usually caused when one's initial grief is focused, not on the person who has died, but on a variety of secondary losses.

After the death of her spouse an elderly widow may, for example, focus initially on losses with respect to income, social status, and social network (i.e., things that are merely associated with the loss of her spouse). In the process she may fail to mourn the actual loss of the person (his touching, holding, kissing, conversation and companionship). Focusing on secondary, peripheral issues serves, in short, to delay the process of grieving.

Whenever we inhibit, suppress, postpone or delay our grief we do a disservice to ourselves. Delayed grief has a way of surfacing with a vengeance later.

6 - 6.3 Exaggerated Grief

With exaggerated grief, the bereaved demonstrates "runaway angst" - a grief that is objectless.

Their despair is entirely out of control and it manifests itself in maladaptive behaviours and psychiatric disorders - among them:

- Depression and despair
- Phobias (e.g., fear of death, feeling alone even when in the company of friends)
- Post-traumatic stress

People who are suffering with exaggerated grief often read the obituaries daily, frequently refer to death in general conversations, routinely wear dark coloured clothing, and often anticipate their own deaths (e.g., "I deserve to die too," "I should have died instead of my spouse"). Like other sufferers of complicated grief, they also tend to engage in self-destructive behaviours like alcohol or drug abuse.

6 - 6.4 Masked Grief

Masked grief is indicative of a severe mental disorder that likely stems from earlier traumatic experiences. People with masked grief rarely reveal their grief. They do not cry; they do not become angry and they remain bereft of emotion. They are often completely self-absorbed - to the point of narcissism.

In other cases, they will develop psychosomatic complaints - symptoms of physical problems that have no physical origin.

The behaviours they demonstrate at the death of a loved one are often designed to cover up personality disorders that were acquired long before - often in their childhood. Most of the people do not realize they are masking their pain and need extensive therapy and counseling.

6 - 7 ANTICIPATORY GRIEF

In situations where a loved one is suffering from a terminal or chronic disease the grieving process may begin long before the moment of death. This is called "anticipatory grief."

Anticipatory grief can be experienced throughout a loved one's illness. There may be a feeling of grief when first learning about their illness. More grief can emerge when it becomes apparent that all the plans that were shared with the loved one are now lost. And still more grief may appear when the person comes to realize that these are the last days, he or she will have together with their loved one.

Of course, the loved one also grieves as he or she comes to terms with a tidal wave of simultaneous losses. Among them: significant physical decline, a loss of independence, a loss of privacy, a declining base of friends, and substantial disruption in their home and community environment. Many will struggle with the fact that there is so much unfinished business that may never be addressed. They often become burdened with feelings of regret for things done, or not done, in the past.

Anticipatory grief can be particularly difficult on the family of people suffering from Alzheimer's disease or other forms of dementia. As the disease progresses, they must come to terms with the fact that the person they knew is already gone. They are forced to witness the "living death" of their loved one. The most difficult part of all is this: they will eventually be entirely forgotten by their loved one - long before the loved one dies.

6 - 8 FACTORS THAT HINDER HEALING

Several behaviours, if maintained beyond the initial period of grieving, can become quite destructive. Among them:

- Using alcohol or drugs to self-medicate
- Immersing oneself in work, or other distractions, to avoid confronting one's emotions and feelings
- Remaining emotionally detached and "numb"
- Ignoring the past, denying that there has been a loss, and focusing almost exclusively on the future
- Distorting the past - either glorifying it or denigrating it to dodge the pain associated with "moving on"
- Avoiding friends and family

Ignoring, distorting, avoiding and detaching oneself from the past are rarely healthy long-term responses to a loss. These responses make it almost impossible for the bereaved to come to any resolution - to close the door on one phase of their life and move on to the next. Worse, failing to come to terms with the death of a loved one can severely compromise future relationships and emotionally sideswipe the survivor at some later date.

6 - 9 FACTORS THAT ASSIST HEALING

- Giving the process time
- Acknowledging feelings - both good and bad
- Using a journal to document and track progress through the process
- Confiding in people that are trusted
- Expressing feelings openly (crying can be medicinal)
- Identifying and resolving unfinished business
- Joining a bereavement group to connect with others who have experienced a similar loss
- Reflecting on and preparing for the changes that will need to occur
- Putting the loss into perspective against "the big picture"
- Acknowledging "the good" that came from the relationship with the deceased - the special memories, the accomplishments, the lessons learned, and the growth achieved
- Remembering all the good things that can still be maintained. Even considering the loss, there may still be a lot of continuity

6 – 10 HELPING THE BEREAVED

Trying to help a grieving person is difficult, time consuming, and emotional experience. The inability to ease or take away the griever’s pain can be frustrating. Yet, providing support to someone who is grieving is an extremely important factor in the grief process, and it can be very personally rewarding if you keep in mind how important your efforts are.

Here are some ideas that may aid you in helping someone who is grieving.

- Find out how the person grieving is feeling by using open-ended questions.
- Ask him or her to identify certain specific needs that he or she might have and help with these.
- Understand that healing is a gradual process.

- Communicate caring in ways other than speaking such as a hug or arm around the shoulders (ask for permission first, sometimes people do not like to be touched).
- Write a note to the bereaved recalling a special memory or quality of the person that died, or how that person influenced your life.
- Encourage the person grieving to talk about his or her feelings.
- Avoid giving advice, or comparing stories, and do not judge the bereaved persons feelings.
- Avoid false reassurances and clichés (e.g., "He had a good life").
- Patiently listen to stories even if you have already heard them many times.
- Do not try to change the way the bereaved is feeling but provide reassurance that their feelings are real.
- Offer calm acceptance of difficult feelings such as anger, hostility, or sorrow.
- Try to help the person direct his or her anger at something other than people or him or herself.
- Do not respond to the loss as though it is replaceable.
- If you had a similar story discuss it only when asked or at an appropriate time.
- Invite the bereaved to do something specific with you at a certain time.
- Encourage the person to do something constructive related to the loss that will help commemorate the loss positively.
- Remind the person how important eating and sleeping well, as well as exercise, are.
- Be careful not to press your spiritual beliefs on others be open to theirs, and gain strength from them yourself and use that to help the person grieving.
- Provide continued support in the weeks and months following the loss through written messages, telephone calls, and invitations.
- Know your own limits and do not try to exceed these.

6 - 11 VARIABLES IN THE GRIEF PROCESS

Every individual will experience grief in a manner that is unique to them. The process will be heavily influenced by a wide variety of different variables.

Among them:

- Social variables
- Physical variables
- Intellectual variables
- Emotional variables
- Spiritual variables
- Financial variables

Some of the specific variables that have a significant influence on the grieving process are covered below.

6 - 11.1 Age

Age - particularly at the extremes (i.e., under age 15 and over age 80) - can alter one's experience of grief. Younger individuals, without the benefit of experience, may struggle to understand death and the challenges it creates. The elderly, on the other hand, may be compromised as a result of a narrowing social network (brought on by mobility issues, sensory challenges, and the previous deaths of close friends and confidants).

6 - 11.2 Sex

Men and women grieve differently. Much of the difference is inherent, but some are the result of certain social stereotypes. Women are expected to cry and to dote. Men are supposed to suck-it-up and be stoic.

Complicating matters further, the current elder population grew up in a world where sexual roles were clearly defined and quite distinct. This tends to place enormous strain on the surviving spouse. Widows may be ill equipped to manage the financial affairs of the household, do basic home repairs, or maintain the car. Widowers, meanwhile, may struggle to prepare healthy and balanced meals, keep the house clean, and do such basic chores as the laundry.

6 - 11.3 Experience

Several people have had the misfortune of experiencing death early and often. Others, however, have been lucky enough to sail through life - well into their middle years - without any experience of death. This will have a significant impact on how these two differing groups react to the loss of a loved one.

6 - 11.4 Personality

Some people are outgoing and expressive - they wear their feelings on their sleeves. Others are reserved, inexpressive and unemotional. Some people like to work through their own problems in private, while others are quite receptive to asking questions, confiding in others and seeking out help. Personality type will heavily influence one's experience of the grieving process.

6 - 11.5 Family Background

The beliefs and attitudes of family, and the way they have responded to death and dying in the past will influence an individual's behaviour. Was there effective communication - were death and dying acceptable topics for discussion?

Did the family believe in life after death? How did family members cope with previous losses? All these issues will have a bearing on how grief manifests itself.

6 - 11.6 Cultural Background

Cultural background has what can only be described as a dramatic impact on the nature of the grieving process. In Italian culture, for example, mourners are expected to cry, and wail, and lament? The Germans, on the other hand, are typically expected to keep their emotions to themselves.

In other cultures (e.g., Irish, Scottish, Polish) the death is to be celebrated - with food and drink and fond memories. It is good practice to learn about the person’s background and how their culture mourns the loss of a loved one.

Still other cultures demand a long ritual period of mourning.

6 - 11.7 Health

Poor physical health, chronic illness and chronic pain can serve to drain a person's emotional energy and make the grieving process more difficult. Conversely, grief can have an adverse impact on all these conditions.

Since aging and chronic conditions tends to go hand in hand, this variable is of concern for the elder population.

6 - 11.8 Social Support System

The presence, or absence, of a strong social network will influence a person's experience of grief. It is highly beneficial to have supportive friends and family and a strong connection with religious and other organizations. Being surrounded by people who care and who are willing to help the bereaved work through their own grief, on their own terms, is closely associated with positive outcomes.

6 - 11.9 Resources

The presence of other, more formal, social resources is also helpful - things like books and tapes on grieving (available from a local library); community based grief counselors; and access to family or group therapy. Even funeral directors have a significant amount of training with respect to grief and grief counseling. It is important that anyone reading books or learning about grief and loss, understand that all the behaviours, thoughts and feelings may not be the same for their experience. Sometimes when people are vulnerable, they try to fit into everything they read in order to 'do' the grief experience right.

6 - 11.10 Financial Wherewithal

Money can solve several problems, while its absence can serve to make a bad situation even worse.

Without appropriate financial resources, a surviving spouse may be forced - during grief - to look for a job, scramble to pay the funeral bills and cover outstanding medical expenses. Grieving becomes difficult amid distractions of this nature.

It is much easier to focus on a loved one and grieve the loss when enough financial resources are available. Better still, if a will and a financial plan were put into place in advance of the death. It can also help to have ready access to professionals in such disciplines as law, accounting and the financial services.

6 - 11.11 Depth of Relationship

How close a person was to the deceased obviously has an important impact on the nature and level of grief.

Did the relationship involve regular close contact? Was some interdependence present? How strong was the emotional attachment? The answer to these questions will have a bearing on the nature of the grief experienced.

6 - 11.12 Preparedness

The amount of emotional preparation made, prior to death, is another important consideration that will influence the grieving process. In some cases, the survivor may have had an opportunity to tell their loved one how much they loved them, how much they will miss them and to ask for their forgiveness for any real or perceived slights. At other times, there may be much that was left unsaid and the slate may be far from clean. If this is the case, the grieving process may be more complex. To fully come to terms with the death, the bereaved will have to do the work of grief and find a way to tie up these loose ends - through prayer, personal reflection, or perhaps by writing a letter to the deceased, to say goodbye.

6 - 11.13 Type of Death

Several variables with respect to how, when and where the death took place will influence a person's grief.

Was death sudden, or did it take place after a long and difficult illness? Was it expected, or a complete surprise? Was it from natural causes, or the result of accidental trauma, homicide, or suicide? Was it untimely (e.g., the death of a child) or in keeping with expectations (e.g., the death of a 90-year-old)? Are there any loose ends (e.g., the cause of death, the circumstances of death, possibly criminal proceedings)?

6 - 11.14 Summary

A review of the above information will make it amply clear, why grief tends to manifest itself in so many ways. Thanks to a multitude of variables, every individual's experience of grief is unique.

The following table provides a handy summary of many of these variables - along with some useful examples.

Table 6 - 1 Variables Affecting the Grief Process

Variable	Examples
Relationship of the Deceased to the Survivor	Grandparent-more expected. Young child – unfair, unexpected
Nature of the Relationship of the Deceased to the Survivor	Strength of Attachment. Dependency on Other for Identity/Function. Plans and Dreams Together.
Type of Death (Natural. Accidental. Suicidal. Homicidal)	Long Illness - anticipatory grieving. Suicide - guilt and shame. A child murdered – rage.
Circumstances Surrounding the Death	Peaceful. Prepared. Communication is Easier. Tragic. Unpleasant - More Difficult
History of Losses	First experience with Death - maybe extremely difficult.
Grieving Pattern of the death	Never grieved earlier. Survivor impact may be doubly traumatic.
Personality Traits of the Survivor	Well-adjusted to life - easier time with grief. Has Pessimistic Outlook difficult time.

Social and Cultural Factors	Loving Family Nearby - easier grieving. Children to care for - Neglect one's own grief. No living relatives - more difficult. Church or community Support- easier.
Other Recent Losses or Stresses	Additional deaths of close family or Friends - more difficulty with grief. Financial Problems - more difficulty.
Disposition of Body & Type of Memorialization	Traditional funeral - cremation. With no memorial - just family.

6 - 12 MYTHS AND MISUNDERSTANDINGS ABOUT GRIEF

As a rule, Canadian society spends very little time and effort discussing grief. It usually only becomes a topic of discussion on a death. Unfortunately, this is often the worst possible time to have an intelligent and meaningful discussion. The atmosphere is emotionally charged, and the people involved are often quite disoriented.

Under the circumstances, it should come as no surprise that several misconceptions and myths - with respect to the grieving process - run rampant.

The following material looks at a number of these "myths."

6 - 12.1 Myth One: Death is death, we all grieve the same way

There will, of course, always be some notable similarities in the grieving process - especially within relatively homogeneous cultural groups or societies. But as noted above, a wide variety of variables also come into play.

The grieving process is heavily influenced by someone's life experiences, age, sex, resiliency, health, cultural expectations and their relationship to the deceased. Everybody "does grief" in their own unique way.

6 - 12.2 Myth Two: Keeping busy can lessen - even eliminate - grief

Individuals often attempt to keep busy as a way of mitigating the pain associated with their grief. They will clean the house, reorganize the closets and engage in a variety of other menial make-work projects.

Distractions of this nature may help the bereaved postpone and avoid the impact of their grief over the short term but not in the long term. Grief will not be denied. Eventually it must be confronted and dealt with.

6 - 12.3 Myth Three: To be bereaved is to be distraught

The death of a loved one can be quite traumatic. Unfortunately, trauma victims do not always behave the way we expect they should.

Often, they simply feel numb, detached and indifferent. It is as if they are in a fog.

This runs counter to society's expectations. We generally expect individuals who have lost a loved one to be openly distraught. When it is discovered that they are, instead, calm, collected and focused we may struggle to understand. We are likely to comment, “My, you sure are taking this well,” or “I expected to find you in a more disturbed state.” Failing to cry, weep and wail in the period immediately after the loss is, in fact, entirely normal.

6 - 12.4 Myth Four: Grief follows a schedule

Sometimes societal and religious beliefs impose a rigid timetable on the grief process. Given the number of variables that come into play and that impact the time it takes to work through the process - applying any sort of timetable is not just inappropriate - it is preposterous. Imagine a widow commenting, "I don't want to mourn for too long, or too short - let's see, a year should do it."

Grief is never so easily managed and scheduled. It runs its' own course on its' own terms.

6 – 12.5 Myth Five: Anger should be suppressed

Anger is a natural response to the death of a loved one and giving expression to it does not make the bereaved a bad person in need of reprimand. Expressing one's anger is, in fact, an important and beneficial part of the grieving process.

Nonetheless, most people are uncomfortable with expressions of anger - particularly in situations where the venting is directed at God. This discomfort is largely misplaced.

As Earl Grollman writes, “It’s okay to scream at God. He can take it.” The Psalms are full of examples of people raging at God over a variety of injustices.

Anger should only be addressed when it gets out of control (e.g., breaking valuables, threatening to kill someone, wanting to vandalize property, contemplating suicide). If this happens professional help and guidance will likely be required.

6 - 12.6 Myth Six: Alcohol and medications can reduce grief

Some survivors will use or increase their use of alcohol or anti-depressants during their bereavement.

In large part, they do this to avoid the pain that comes from facing up to - and coming to terms with - their feelings. Excessive use of alcohol and drugs can also distance the bereaved from their family members, friends and other support groups.

In these situations, grief simply goes underground and waits to be expressed later. The bereaved often believes - mistakenly - that the grief will disappear after a period, whether it is addressed or not. Nothing could be further from the truth.

Having said this, it should be noted that some individuals may require medications in the short term - not to avoid grief - but to ensure that they can function.

6 - 12.7 Myth Seven: Talking about the loss makes matters worse

Grief must be experienced. Hiding it, denying and failing to talk about it will only serve to prolong it. Meeting with other people to talk about one's grief can help the bereaved to work through the process.

In *Living with Loss: Meditations for Grieving Widows,* Ellen Sue Stern writes, “It is essential to allow yourself to talk as much as you want; healing is hastened by reminiscing about your husband [or loved one], processing the last days of his life, the funeral and any other details surrounding his death. For now, choose only to spend time with people who are supportive and understanding, who can lovingly listen as long as you need to talk.”

6 - 12.8 Myth Eight: After a while, the loss will be forgotten

People who believe they can forever put the loss and the circumstances surrounding the loss "out of mind" are sorely mistaken. From time to time, for the rest of their lives, the loss itself and the feelings it invoked will come rushing back.

It is not uncommon for the bereaved to be ambushed by grief when they least expect it.

6 - 12.9 Myth Nine: A quick painless death is a blessing

After a sudden death, it is not uncommon for people to announce: “well, at least he died quickly—be happy for that. He was spared the pain of a long, slow and debilitating illness." It is a nice sentiment. Unfortunately, loved ones may not see it this way - they may not be inclined to go along with this tidy little rationalization.

To them the sudden passing of a loved one is untimely —something that occurred far too soon - without any opportunity to prepare, without a chance to say "goodbye." They will likely find very little, if any, relief in the knowledge that their loved one died quickly.

6 - 12.10 Myth Ten: Grief is a linear process

As noted earlier in this chapter, grief is not a linear process.

Grief is not an elevator that starts at the basement of despair and then rises without interruption to the penthouse of relief. Instead, it is more like a maze full of dead ends, detours and roadblocks. Repeatedly, the bereaved are forced to retrace their steps in order to find the way out.

6 - 13 HELPING ELDERS THROUGH THE GRIEVING PROCESS

A variety of different approaches, actions and strategies can be employed to help elders cope with the challenges that grief presents:

- Small, but meaningful, gestures goes a long way (e.g., - a phone call, a card, a hug)
- Simply being available is quite helpful - it allows the elder to express their feelings, on their own schedule, without any sense of urgency
- Being patient - even when the elder retraces old territory repeatedly
- Being a good listener - taking in what they say without being judgmental, without telling them what to do, and without resorting to clichés (e.g., "You have to move on," "it's for the best")
- Encouraging self-maintenance - it is a slippery slope if they start to let themselves go. Encouraging a healthy lifestyle
- Knowing when to access outside expertise - everyone has limitations and there is nothing wrong with using such outside resources as books, support groups, other friends, and professional counselors

In addition, grieving elders should be encouraged to do all the following:

6 - 13.1 Postpone Major Life Changes

Elders may be tempted to make major decisions impulsively while in the throes of their own grief. Often these decisions prove to be ill advised and far from in their own best interests. They should be discouraged from selling their home, moving to a new geographic location, or making large discretionary purchases. Often decisions of this nature are driven by a grief stricken elder's need to escape their current circumstances. Major changes of this nature, often, only provide a "temporary fix."

Elders should be encouraged to postpone any major decisions for at least a year after the loss of their spouse. By then they should be able to make decisions that are less rash, more measured - and which have been vetted by close friends and family.

6 - 13.2 Ask for Help

Many friends and family members may be more than ready to help the elder adjust - but they may not have any idea what - specifically - would be of assistance. They should let the elder know that they are available - on an open-ended basis - and then encourage him or her to ask for whatever help he or she deems appropriate.

Once asked to assist, it is vitally important to carry out the task without judgement or complaint and to reassure the elder that it is not, in any way, an inconvenience.

6 - 13.3 Turn to Others

Elders should not be shy about letting others know they are still struggling with their loss. There is no reason to hide their grief. In order to help, the people around the elder need to know how the elder is doing - what they are feeling and what their state of mind is.

Dissembling serves no purpose.

6 - 13.4 Keep Expectations within Reason

Grieving elders should be encouraged to keep their expectations reasonable. Ideally, they should focus most of their energies on the things that need to be done and on things that they want to do.

Often elders will try to do far too much after the death of a loved one - and much of their agenda will be driven by what they assume are the expectations of others.

They should not be driven by the things that they feel that they "should do" or "ought to do." Trying to live up to the expectations of others is especially hard on the bereaved and it should be discouraged.

It is far better for the elder to take comfort of enjoyment from the things that are on their own agenda:

- Telling stories about their life
- Participating in different forms of creative expression, such as art and music
- Maintaining a journal
- Seeking support and encouragement
- Sharing their spiritual and emotional journey with loved ones

6 - 14 REINVESTING IN LIFE - MEMORIALIZING THE DEAD

Eventually the bereaved will find ways to become engaged in life again. With their spouse now gone a survivor might develop a new hobby or interests - perhaps even apply for a new job. They may also develop new friendships - or reinvest in old ones.

Part of this reinvention will involve finding ways to memorialize and honour the deceased. Some people create special areas in their homes where they arrange items that belonged to loved ones (collections, books, photographs, and trinkets) to serve as glad reminders. Others arrange for special services, at their place of worship, to be dedicated to the deceased - especially on key anniversaries. Some families visit the graveyard on a regular basis to maintain a connection. Still others plant a tree or create a garden or other memorial in a special place.

Charitable gifts can also play a part in helping to remember and honour the deceased. One woman donated books to a school library, with special bookplates, in her aunt's name.

As a survivor reinvests in life, he or she may feel certain pangs of guilt. In finding pleasure in life, they may come to feel that they have abandoned and forgotten the loved one who has died. Honouring their memory, with regularity, helps to address this guilt - both the loss and a satisfying new life can co-exist.

One mother, writing about the loss of her teenage daughter states it most eloquently: "The memory does not go away when you start to heal and, living a full life does not deny the emptiness left by the loss."

6 - 15 CHILDREN'S UNDERSTANDING OF DEATH

Even if an individual is well equipped to handle their own loss and assist other adults in the process - they may find it difficult to help a child come to terms with death.

Children grieve, often quite deeply and for an extended period. Their experience of grief and the way they express it may be different, but it will be no less painful than what is typically experienced by an adult.

As a result, children require the same kind of support that is typically given to adults. Lots of attention and love, companionship, someone to talk to and someone to cry with. The more sharing and communication that takes place, the better - it allows children to begin to understand, to cope with, and to integrate the experience of loss into their lives.

The following material outlines some of the strategies that can be employed to help children adjust to the death of a loved one.

6 - 15.1 Keep It Simple

Encourage children to express what they think, know, and feel - and be prepared to answer their questions simply and directly. Do not overwhelm them with excessive detail.

6 - 15.2 Be Honest

Avoid half-truths. Do not tell a child something you will need to correct later. For example, if a child insists that “Nana or Papa will be back in the spring... just like the flowers,” you should not - out of misplaced compassion - agree. Instead, you can say something like “That would be nice, wouldn’t it?”

6 - 15.3 Make an Effort - Silence Is not Helpful

Even the clumsiest statement is better than not discussing the loss at all. Children are quite aware when they are being shut out and ignored. If this happens, they may respond with a variety of disruptive behaviours - angry outbursts, irritability and even changes in eating and sleeping habits. The best solution is open communication.

6 - 15.4 Expect Expressions of Anger

Some anger is to be expected - anger directed variously at a "higher power," at the lost loved one, at a surviving parent, at the doctors, at anyone who is readily available. Children may even come to blame themselves for the loss (because of a recent incident or conversation).

6 - 15.5 Monitor Their Play

Monitoring their play can offer valuable clues to how children are managing the loss, particularly in the case of very young children. Young children often express feelings that they cannot easily verbalize, by acting them out with dolls or toys.

6 - 15.6 Be Prepared for Muted and Delayed Responses

Do not be upset if, after a clear explanation of what happened, children appear to toss it off and carry on with their normal activities. It takes time for children to internalize "bad news."

In situations like this, prepare for an emotional response and several tough questions later - perhaps even months later. It is at this point that many children will confront their biggest fears.

The ***four*** crucial questions that they will have are:

1. Did I cause the death?
2. Will I die too?
3. Are you (i.e. the parent) going to die?
4. If you die too, who will take care of me?

6 - 15.7 Involve Children

Try to include grieving children in the events that precede and follow a death. Encourage the child to say goodbye in the hospital, to attend the funeral service, and to participate in rituals with the family.

They can cope with most situations if they are given choices, offered opportunities to talk, prepared for what to expect, and supported emotionally. Simple ceremonies such as lighting a candle next to a photograph, placing a letter, picture, or special memento in a casket, or releasing a helium balloon, with a message attached for the deceased, are effective leave-taking gestures.

6 - 15.8 Make Use of Outside Resources

Children - especially adolescents - may require help to express their grief, especially over the loss of a parent. Adolescence is a difficult enough passage and grief adds layers of complexity and emotion. Address a teenager's need early and often and ask the child's school for help or guidance.

Use books, TV, and movies to help during this process. Many wonderful after-school specials and prime-time programs deal with the death of a parent, grandparent, sibling, or pet. "The Yearling", "All the Way Home", and "Death Be Not Proud" are available for rent.

Among the many wonderful books written for younger children is "Badger's Parting Gifts" by Susan Varley. Old Badger dies, leaving a note for his friends: "Gone down the Long Tunnel. Bye Bye, Badger." His friends—the mole, fox, and rabbit—talk about the things each learned from Badger, realizing that he has left them many good memories and abilities. This book is a great platform from which to talk to a child about an older relative who has died or who is dying.

6 - 16 MUSIC AND MOURNING

For as long as there has been music, there has been music to help people through times of sadness. The origins of most Western music can be found in the Gregorian chants of medieval monks. Sometimes the chants were written for everyday prayers, but frequently they were written for funeral masses. From those beginnings, a tradition of funeral songs, or requiems, continued in classical music to the present day.

Jazz music has long been played at New Orleans funerals. Sad songs are played at first, and then happy songs to celebrate the deceased and share the joy of his entering a better life. Show tunes, rock and roll, folk songs, and gospel hymns all, often, deal with loved ones dying.

Music offers comfort without making any demands on people at all. When singer and guitarist Eric Clapton's son died tragically and suddenly, he wrote a song for him called "Tears in Heaven." This beautiful song struck a chord with many people. For those who had lost a child, hearing someone else mourn a similar tragedy helped them to feel less alone in their grief.

No matter the reason, music helps you turn a flood of emotions into something more manageable. With or without lyrics, melodies communicate and interact with the soul. That is why so many cultures use music and why some songs cross many cultures with ease.

The music people use is as diverse as people themselves—from electric guitars to trumpets to choirs, from slow and soft, as in Mozart's "Lacrimosa," to bright and crisp, as in "When the Saints Go Marchin' In." Often people choose to listen to something that was special to the person who has died. There may also be a special song or tune that has helped before in other times of struggle and may help again now.

Having music around provides a rhythm, a structure around which you can reflect and grieve. Like a metronome, or deep breathing, it gives a rhythm to fragmented thoughts.

Music also has the powerful ability to draw out memories obscured by time or emotion. It seems to have a near-magical ability to penetrate through the present day to remind you of other occasions. Sometimes songs and melodies so accurately pinpoint an emotion that they transport the listener to another time and place.

Sometimes in times of sadness and shock, people have merely felt numb. Certainly, this is a protective mechanism, a perfectly normal approach to grief and nothing to be ashamed of. However, sometimes music helps evoke welcome thoughts and feelings.

6 - 17 SUPPORT SERVICES

If the support provided to a bereaved individual, by family and friends, is not enough there are a variety of other more formal sources of support. Among them:

Bereavement Support Groups

Often, the best way to cope with loss is to talk to others who have had similar experiences. Many hospitals and hospices offer grief and bereavement support groups that meet regularly over a period of months. The bereaved are encouraged to share experiences, thoughts, and memories. Talking with others can have a healing effect.

Many of these programs are tailored to meet very specific needs. People whose children have died, for example, tend to have issues and concerns that are quite different from individuals whose spouses or parents have died.

One on One Counselling

Approximately one third of people in mourning turn to clergy or spiritual leaders for support. Specially trained members of the clergy, called pastoral counselors, are available in most major centres to assist with spiritual and emotional healing.

One on one counseling is also available from: hospitals, hospices, palliative care organizations, funeral homes and charitable organizations.

Literature

Literature can be of great assistance to the bereaved. The following popular titles offer both insight and comfort.

- "A Grief Observed" by C. S. Lewis (Doubleday, 1961)
- "A Letter of Consolation" by Henri Nouwen (Harper, 1982)
- "Andrew, You Died Too Soon" by Corinne Chilstrom (Augsburg Fortress, 1993)
- "Don't Take My Grief Away" by Doug Manning (Harper, 1979)
- "Dying Well" by Kenneth and Sara Vaux (Abingdon, 1996)
- "Five Cries of Grief" by Norton and Irene Strommern (Augsburg, 1993)
- "God, Medicine and Suffering" by Stanley Hauerwas (Eerdamans, 1994)
- "Good Grief" by Granger Westberg (Fortress 1997)
- "Grief Therapy, The Self-Help Series" (Abbey Press, 1985)
- "Life After Loss" by Bob Deits (Fisher Books, 1992)
- "On Death and Dying" by Elizabeth Kubler-Ross (Collins-MacMillan Canada, 1969)
- "The Tree That Survived Winter" by Mary Fahy (Paulist Press, 1989)

- "Water Bugs and Dragon Flies" by Doris Stichney (Pilgrim Press, 1982)
- "When Death Has Touched Your Life" by John Biegert (Pilgrim Press, 1981)
- "Winter Grief, Summer Grace" by James Miller (Augsburg, 1992)
- "Understanding your Grief" by Alan D. Wolfelt (Companion Press, 2003)
- "The Handbook for Companioning the Mourner" by Alan D. Wolfelt (Companion Press, 2009)
- "The Wilderness of Grief: Finding Your Way" by Alan D. Wolfelt (Companion Press, 2007)

6 - 18 CONCLUSION

People are born into families. They grow and live surrounded and supported by a strong and elaborate social network. It is part of their makeup to form strong bonds with the people around them.

The price they pay for these attachments is vulnerability—the risk of loss.

When someone you love is gone from your life, it is as if a piece of you has been torn away. The loss rends the very fabric of your existence and the wound must be repaired. For people to go on with their lives and again risk caring about others, they need to let go of the people they love who are no longer with them. Grief is the process through which the mind heals the hurt. It is what allows human beings to gradually accept a loss.

At the end of mourning, there will still be sadness. But hopefully it will be a wistful sadness, tempered by happy memories.

Having a solid grounding in matters concerning loss, bereavement and the grief process cannot help but be of assistance to anyone who works with elderly Canadians.

We conclude this chapter with a quote from a 1999 Television movie, "Tuesdays with Morrie:"

“Death ends a life…not a relationship”.

6 - 19 REFERENCES

Canadian Mental Health Association, Ontario Division

T. J. Glenn, M.D., F.A.P.A., F.A.A.C.A.P. - 20450 Huebner Rd. #203, San Antonio TX 78258

Centre for Loss and Life Transition, 3735 Broken Bow Road, Fort Collins,

Dr. Elisabeth Kubler Ross

Grief Counselling & Grief Therapy: A handbook for the mental health practitioner, 2nd Ed. New York: Springer.

Kathleen Braza, M.A., Bereavement Consultant, Healing Resources, Salt Lake City,

Lynn, J., Schuster, J., and Kabcenell, A. (2000). Improving Care for the End of Life: New York: Oxford University Press.

Grief or Loss, National Caregivers Library, 2013

Topical Index

Table of Figures

CHAPTER 1 – Long Term Care Issues

CHAPTER 2 - Housing Options

CHAPTER 3 - Caregiving in Canada

CHAPTER 5 - Funeral Planning

CHAPTER 6 - Bereavement - Grief & the healing process