a guide to end-of-life care for seniors

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Readers are cautioned that therapies and clinical recommendations in the field of end-of-life care and seniors are ever-changing. This publication is provided for reference only. It does not replace the discretion and judgement of the individual caregivers in the care of seniors at the end of life.

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chapter 1

TOWARD OPTIMAL CARE

INTRODUCTION

Goals of this Chapter are to:

- present an overview of the issues related to end-of-life care for Canadian seniors
- provide the purpose and rationale for developing a guide for end-of-life care for seniors
- establish a common understanding of end-of-life care, palliative care and geriatric care
- dispel myths and misconceptions of dying in later life

Death is a natural stage in the cycle of human life and in an "aging society", such as Canada, the care of seniors at the end of life becomes a national priority. Canada's population has been aging dramatically. Currently, there are approximately 3.7 million Canadians aged 65 and over; by 2021, 6.9 million Canadians will be 65 and older. It is also clear that the majority of people die in their later years. In spite of this demographic imperative, the emphasis on end-of-life care has tended to focus on the needs of younger people with cancer or HIV/AIDS and not on the needs of seniors.

A GUIDE for end-of life care for seniors is necessary because many needs for older people are different from those of younger people. For seniors, the end of life may be associated with chronic conditions and other diseases. These may include cancer (the majority of new cancers are found in persons over the age of 60 years), congestive heart failure, chronic obstructive airway disease, stroke and the complications of dementing illness. Given the multi-systemic nature of illness at the end of life for seniors, the pattern of symptoms is equally diverse and may include pain as well as such symptoms as: dyspnea, dysphagia, edema, shortness of breath and delirium. Furthermore, the multi-systemic nature of illness at the end of life for seniors creates its own challenges related to disease and treatment interactions. The trajectory of death for seniors is less predictable, often punctuated by a series of acute events. Dying may occur in long-term care settings, in the home or in acute care hospitals.

What is our life expectancy?

- In 1991, Canadians 65+ had a life expectancy of 18 years, nine of which were expected to be disability-free, while the remaining nine years were expected to include three years each of slight, moderate, and severe disabilities.[1]

Seniors often become frail from advanced aging and they may suffer from chronic health limitations. What diseases are Canadian seniors dying from?

Men:

- Coronary heart disease
- Lung cancer
- Stroke

- Other causes of death include: chronic bronchitis; emphysema and asthma; prostate cancer; pneumonia; colorectal cancer; diabetes mellitus; urinary cancer; aortic aneurysm

Women:

- Coronary heart disease
- Stroke
- Lung cancer
- Other causes of death include: pneumonia; breast cancer; colorectal cancer; chronic bronchitis, emphysema and asthma; diabetes mellitus; Alzheimer's Disease; kidney disease[2]

What are the leading causes of hospitalization for Canadian seniors?

Men:

- Coronary heart disease
- Cerebrovascular disease
- Prostate disease

Women:

- Coronary heart disease
- Accidental falls
- Cerebrovascular disease[3]

What proportion of seniors experience pain or discomfort?

Of older people living in a private household:

- 30% of those 65-74 experience pain and discomfort
- 35.1% of those 75 and over experience pain and discomfort[4]

Of older people living in an institution:

- 31.9% of those 65-74 experience pain and discomfort
- 37.3% of those 75-84 experience pain and discomfort
- 35.3% of those 85+ experience pain and discomfort[5]

What proportion of seniors have Alzheimer Disease?

- Alzheimer Disease is a significant illness of later life as it presently affects 316,000 Canadians. This number is expected to increase to approximately 750,000 in the next 30 years. It is also known that approximately 25% of people aged 85 and over have Alzheimer Disease; however, one in three Canadians over age 85 are affected by Alzheimer Disease and related dementias.
- 67% of people with this disease are women.[6] 50% of people with dementia live in institutions such as nursing homes, homes for the aged or retirement homes; however, those living in institutions have a greater severity of dementia.[7]
- Alzheimer Disease is probably the fourth or fifth leading cause of death among seniors, though these data are difficult to obtain as Alzheimer Disease is often not listed as a primary or secondary source of illness on the death certificate.[8]

These statistics on illness at the later stage of life suggest that a large number of seniors will need end-of-life care over a significant period of time. It is well-known that palliative care programs provide excellent end-of-life care for short periods of time. In many palliative care programs, the time limit of care is less than 90 days and they usually target cancer patients. More recently, other palliative care programs have extended their interventions to a multidisciplinary approach. In these programs, the trend is to work with patients at the time of diagnosis, through the chronic process, and into the palliative phases. Therefore, for older people who are dying from protracted illnesses, we will speak of "end-of-life care for seniors" rather than palliative care only. We feel that this distinction better describes the process by which seniors will receive adequate care at the end of their lives.

End-of-life care for seniors affects many components of individual and population health. Continuing advances in medical technology and the compression of morbidity in the last years of life, together with health care reform and the emergence of profound bio-ethical debate will generate great public attention. The end-of-life needs of a culturally-diverse population and Aboriginal peoples will become more widely recognized and the burden of middle-aged people caring for dying parents and children will affect both family life and the workplace.

Fortunately, Canada has the expertise to address the complex issues related to end-of-life care for seniors. There are a great number of health care and social service professionals practicing excellent end-of-life care for seniors throughout the provinces and territories of the country using multidisciplinary and interdisciplinary approaches. There are also a large number of researchers and educators developing improved and compassionate ways to provide end-of-life care for seniors. Finally, there are also dedicated health care and social service policy makers and administrators who are contributing to excellent end-of-life care for seniors. Given the considerable expertise of all these professionals in Canada, it is opportune to develop a guide to reflect a national consensus on knowledge and skills about excellent end-of-life care for seniors.

PURPOSE OF THIS GUIDE

This GUIDE supports the end-of-life care of seniors that reflects a consensus of best practice in this area of health care and social service delivery. This GUIDE was developed by having the National Advisory Committee establish the table of contents, having lead expert authors write a first draft of the chapters, having this first draft reviewed by the members of the National Advisory Committee, having the lead expert authors revise their chapters based on this review, sending the revised GUIDE to Canadian and international experts for comments, revising the GUIDE based on this review, and having the members of the National Advisory Committee review and approve the final draft of the GUIDE. The main audience for this GUIDE is health care and social service providers in long-term and acute care settings and in community care agencies. The GUIDE will also be useful and informative for seniors and their family caregivers, health care planners, students and the general public.

This GUIDE links end-of-life issues to the major determinants of population health. It supports effective decision-making in the context of continuing advances in health care technology and the socio-economics of health care reform. It also reflects the diverse needs of Canada's Aboriginal peoples and the cultural mosaic of our population and addresses the impact of end-of-life care on family and working life.

This GUIDE emphasizes and encourages the collaborative nature of end-of-life care for seniors, supports personal health practices and decision-making, and strives to fulfill the adage that effective health care is able "to heal sometimes, to relieve often and to comfort always".

The Goals and Objectives of this GUIDE are:

To improve end-of-life care for seniors by:

- consolidating "best practices"
- providing a national guide for everyday practice
- developing a common language for the practice of care
- facilitating increased autonomy and independence in decisions by seniors

RATIONALE FOR A GUIDE FOR END-OF-LIFE CARE FOR SENIORS

Seniors make up a significant portion of Canada's population. In 1995, people aged 65 and over represented 12% of the total population,[9] and they make up one of the fastest growing population groups in Canada. It is projected that by the year 2016, 16% of all Canadians will be aged 65 and over.[10] These numbers mean that more seniors will need end-of-life care than ever before. It is important that there is a clear guide on caring for these seniors. It is very important that health care professionals who work with patients and their families receive a basic grounding in how to competently and compassionately care for seniors at the end of life.

- Many seniors suffer chronic health problems or develop severe illnesses that progress to a terminal phase. When an incurable disease occurs, end-of-life care geared to the special needs of seniors is required. These needs include palliative care, including respite care for family members. These needs also include the training of caregivers in the treatment of seniors, with a greater focus on the understanding of depression in older people and how it affects terminally-ill seniors.[11]
- There is a need for consensus and action to improve care for seniors who are near the end of life.
- Confirmation is needed to define life-sustaining treatment components including advance care planning, decisions to withhold or withdraw life-sustaining treatment and appropriate use of life-sustaining treatment.[12]
- The characteristics of care that are particularly relevant to later life such as naturalness of dying, heightened awareness of finitude, diagnostic and prognostic complexities, trajectory of illness and dying, among others, must be more publicly discussed.
- There is a need to improve the quality of dying for seniors for whom some physical outcomes become less realistic while other outcomes such as spiritual well-being or sense of peace may become more meaningful.
- Homecare services are critical factors in making dying at home possible, for those who wish to have this option.[13] This means that homecare professionals need to have a clear framework of end-of-life care and all that it entails.

The prevalence of progressive or chronic life-threatening conditions in later life challenges the health care delivery, finance, research and education systems that are designed primarily for acute illness and injury. Overtreatment in end-of-life care is as greatly feared as is abandonment.

- It is important that the self-determination of chronically-ill, institutionalized seniors who may want to die quickly and painlessly with as much privacy and dignity as possible is respected at the end of life.[14]

Seniors tend to have more complex health problems than younger people and may require different strategies or interventions in the control of pain. For example, many seniors are being treated for cancer while they also suffer from other chronic illnesses such as diabetes, glaucoma, and rheumatic disorders.[15] Furthermore, seniors may also suffer from difficulty with breathing, general discomfort, weakness, loss of appetite, dehydration, inability to swallow, confusion, problems with thinking and memory loss, and incontinence. For this reason, it is often difficult to identify the source of the pain. Physicians must also be aware that seniors react differently to narcotics and that they need to prescribe accordingly.[16]

CLARIFICATION OF TERMINOLOGY

END-OF-LIFE CARE, PALLIATIVE CARE, GERIATRIC CARE: COMMON GROUND AND DIFFERENCES

There is common ground among the terms "end-of-life care", "palliative care" and "geriatric care" with respect to treating and caring for seniors. These three kinds of care all attempt to provide excellent care to seniors. In theory, each of these kinds of care provide comfort and relief for seniors for a specific period of time. End-of-life care for seniors and palliative care needs to be available on a continuum. Many older people at the end of life are not designated as "palliative" for various reasons so that palliative care is not made available to them. Also, many seniors do not have a health care and/or social service provider who is specialized in geriatric care. End-of-life care for seniors is more specific than geriatric care, which encompasses the whole range of aging and does not focus specifically on end-of-life issues and challenges. End-of-life care for seniors also has a particular focus that palliative care, to date, has not fully encompassed (e.g., care of seniors who are dying from a chronic and progressive condition such as Alzheimer Disease). Palliative care programs are expanding to include care for these chronic conditions. Seniors with chronic diseases for whom death is becoming increasingly predictable benefit from care that links and expands geriatric care and palliative care.

DEFINITION OF END-OF-LIFE CARE FOR SENIORS*

The following definition of end-of-life care has been developed by the National Advisory Committee of this project. It borrows from the work that has been done in both palliative care and geriatrics and attempts to integrate their philosophy and principles of practice.

End-of-life care for seniors requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement.

PALLIATIVE CARE FOR SENIORS

The Canadian Palliative Care Association defines palliative care as "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 main 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."[17]

A salient feature of palliative care is the recognition that death is inevitable and imminent. The Edmonton Palliative Care Program[18] referred to palliative care as the active total care offered to patients with progressive disease and their families when it recognized that the illness is no longer curable, in order to concentrate on the quality of life and the alleviation of distressing symptoms in the framework of a coordinated service. The focus of palliative care is neither

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* Definitions for end-of-life care and palliative care are also discussed in Chapter 5.

to hasten nor postpone death. It provides relief from pain and other distressing symptoms and integrates the psychological and spiritual aspects of care. Furthermore, it offers a support system to help relatives and friends cope during the senior's illness and bereavement.[19]

GERIATRIC CARE

Geriatric care is typically viewed as the care of persons who are aged 65 and over. Geriatric care encompasses a wide range of treatment from intensive care to palliative care.[20] It can work together with palliative care to meet the needs specific to the senior. Such care, which is proper and appropriate for older people who are dying, includes symptom control, care within seniors' facilities, continuity of care, flexibility and multidisciplinary teamwork. Today, however, many palliative care programs are delivering care which encompasses geriatric care by using an interdisciplinary approach.

MYTHS AND MISCONCEPTIONS OF DYING IN LATER LIFE

There are many myths and misconceptions related to dying in later life. We feel it is important to present these myths and misconceptions in order to dispel them.* Some myths and misconceptions of dying in later life are:

Seniors don't need end-of-life care as they are going to die anyway.

Many seniors would choose to continue living even if they were to have a terminal illness.[21] Issues of self-care, emotional support, nutrition and pain control have been found to be the most significant management issues for older people in their last years of life.[22]

Most seniors die in long-term care facilities and therefore receive end-of-life care.

Only 39% of Canadians die each year in long-term care facilities. There is a need for education on many issues relating to palliative care in nursing homes.[23] Issues include stress management for staff members, physiological impact of illness, assessment and management of pain, management of the psychological impact of death on seniors, other residents and families, legal implications and advance directives.

Seniors are completely prepared for death.

Barriers such as a senior's indecision, ambivalence or denial can hinder the development and implementation of advance directives and preparation for death. However, health care and social service providers and families have the ability to help older people decide what kind of health care they would like to receive if they become terminally ill.[24]

Seniors die of old age.

Aging itself does not cause symptoms, let alone death. Seniors die of many different illnesses. In 1994, heart disease was the leading cause of death among seniors. At that time, 31% of all deaths among Canadian seniors were attributed to heart disease while 26% were due to cancer, 11% were related to respiratory diseases and 9% were due to strokes.[25]

There is nothing that can be done for seniors who are dying.

There are many things that can be done. Health care facilities can inform seniors about their rights and can also support residents, family and staff members in exploring end-of-life decisions before a crisis emerges.[26] It is important

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* Additional information on this topic is in Chapter 5.

that the older person have some control over end-of-life decisions. Many seniors want the opportunity to decide and/or share decisions with their families and caregivers.[27] Family caregivers are also important people to consider when taking care of a senior who is dying. They play a very important role in taking care of the family member who is dying and they require emotional support that will allow them to continue to care for their loved one.[28] There is much that can be done to enhance the quality of life for the senior and for the family and formal caregiver.

QUALITY OF LIFE AT THE END OF LIFE

Quality of care at the end of life means ensuring that the right care is being provided at the right time in the right way. Overuse and underuse of care may occur simultaneously, for example, when futile efforts to cure are continued at the expense of efforts to relieve physical and psychological symptoms and help seniors and families prepare emotionally, spiritually, and practically for death. Untimely referral to hospice and palliative care is a form of underuse as is inattention to patient and family needs for nonmedical support. Poor technical performance, such as miscalculation of medication dosages for pain or other symptoms, has been little studied.[29]

- Quality care at the end of life is often characterized by problems in the following areas:
    - overuse of care (e.g., unwanted treatments or hospitalizations; diagnostic tests that will not inform patient care but may cause physical and emotional distress)
    - underuse of care (e.g., failure to assess and treat pain; late referral for hospice care, premature hospital discharge)
    - poor interpersonal performance (e.g., inept communication of difficult news)
- For improving end-of-life care by health care and social service providers at the bedside, three main elements should be included:
    - Comfort: control of pain and other symptoms. No senior should die in pain or with other treatable symptoms.
    - Decision-making: the use of life-sustaining treatments. The older person and family should be able to choose the care the individual will receive in the last days of life.
    - Support: of those who are dying and their families. Support needs are unique to the senior and family and can be met by an interdisciplinary health care team.[30]
- Issues to consider with respect to quality end-of-life care include: treatment of physical and emotional symptoms, support of function and autonomy, advance care planning, patient and family satisfaction, global quality of life, family burden, survival time, health care and social service provider continuity and skill, and bereavement.[31]
- Patient circumstances and goals can help establish a more specific meaning of quality of care. Desired outcomes for a dying patient will differ in some ways from the outcomes desired when prevention of a disease is still relevant or cure is still possible. Even for seniors diagnosed with incurable illnesses that are likely to prove fatal within a matter of months, the outcomes that are meaningful early in the dying stages such as physical functioning and independence may become less so as the progress of the disease continues. The imminence of death makes such outcomes less realistic and heightens the relevance of physical and emotional comfort, resolution and growth in personal relationships, and issues of spiritual meaning or peace.[32]

CONCLUSION

End-of-life care for seniors must be an integral part of dying in later life. We all know of seniors who have died well and seniors who have had a difficult death. Based on this knowledge, we would all wish for a kind and gentle death in later life for our loved ones and for ourselves.

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chapter 2

LIVING AND DYING WELL IN LATER LIFE

INTRODUCTION

Goals of this Chapter are to:

- explore effective support mechanisms for seniors, caregivers and health care and social service providers
- recommend effective methods of providing care when confronted with the challenges associated with end-of-life issues
- explore effective care delivery mechanisms, their components and the principles and values attached

Three underlying themes are central to optimal end-of-life care - **comfort, communication**, and **support**. **Comfort** is central to effective end-of-life care. It is obtained physically through pain control, but also through social support and recognition of the senior's fears and search for meaning in his/her experience. **Communication** is a tool that is used to share information and provide comfort. It is vital for creating and maintaining effective relationships as well as for effective decision-making. **Social support** provides the context for end-of-life care. This chapter also assumes the following principles of care:

- Timeliness: discussing end-of-life decisions while seniors are able to communicate their preferences and before immediate decisions are necessary
- Openness: willingness to address difficult issues
- Honesty: providing all known details about the illness and prognosis[1]
- Autonomy: encouraging and helping seniors and families to make decisions and act independently

DYING WELL

Seniors' abilities to age well are partly shaped by how they experienced earlier stages of life. In turn, aging well influences the ability to die well. How is "dying well" measured? A prime consideration is whether the person is dying in the way he/she prefers. Individual preferences are shaped by:

- personality
- gender
- ethnic background
- social class
- culture
- spiritual beliefs

The individual defines dying well for himself or herself; those assisting the dying person contribute by satisfying the psycho-social, emotional and physical needs of both the dying person and his/her survivors.

A good death may include elements such as:

- being pain-free
- operating at the highest possible level of functioning
- resolving long-standing conflicts
- satisfying final wishes
- relinquishing control over care to significant others[2]

In order to experience a good death, seniors may want to be fully informed of their condition and offered the opportunity to choose or reject care. As the dying person's condition deteriorates, others often have to take control. The potential to die well thus depends largely on the senior's relationship with caregivers.[3]

The degree of awareness that the dying person has can also influence the ability to experience a good death. "Open awareness" includes the knowledge that one is dying and is associated with a feeling of satisfaction with having sufficient choice about end-of-life circumstances. People with "open awareness" are more likely to die at home and to have a smoother, more planned approach to final admission to hospital, hospice, palliative care or long-term care. "Closed awareness" involves a situation where people who are terminally ill are not fully aware of their prognosis and are more likely to have rushed emergency deaths in hospital.[4]

Coping skills can also influence the capacity to experience a good death. Of course, coping mechanisms used vary from person to person. The Canadian Needs Study found that people who are terminally ill coped in accepting their illness by sharing their concerns with others and confronting their situation in practical ways such as making plans for their family, preparing wills, and accepting treatment.[5]

While discussion of the dying person's wishes may be viewed as ideal to health care and social service providers, this does not always happen. This may be due to religious or cultural beliefs, denial or individual coping style, on the part of the senior, health care and social service provider or family. In addition, several factors impede communication between service providers and seniors:

- physical impairments such as poor sight or hearing
- tendency not to question authority and to be passive, especially when others are present
- restrictive characteristics of the provider including ageism, lack of compassion, a reluctance to discuss end-of-life issues and lack of time[6]

Even though death is a defining event in later life, there is a lack of knowledge about the meaning of death for seniors. Although death occurs most frequently in the senior population, most research on the experience of dying has examined younger populations.

In general, good end-of-life care:

- enhances the senior's quality of life and, in some cases, lengthens the amount of time that the person can contribute to society
- contributes to the health and well-being of loved ones[7]

The elements of "dying well" covered in this chapter are linked to several determinants of health. Determinants of health are factors and conditions that influence health status throughout life. These, in turn, have an impact on well-being at the end of life. The following chart[8] demonstrates the determinants that pertain to this chapter:

DETERMINANT OF HEALTH	GOALS OF END-OF-LIFE CARE
Health Services	Controlling pain and other symptoms Optimizing physical functioning Providing timely care
Personal Health Practices and Coping Skills	Fostering a sense of control Eliminating fear and anxiety Allowing the freedom to die well, according to the patient's choice
Social Environments	Providing a supportive atmosphere for strengthening relationships Providing opportunities for social contact
Culture	Providing care that is consistent with cultural values, beliefs and practices Providing access to spiritual guidance and ensuring freedom for spiritual practices
Income and Social Status	Encouraging the use of planning tools (e.g., powers of attorney, wills) Avoiding impoverishment due to illness

As will be shown in this chapter and the rest of the GUIDE, there are many factors that can influence a good death. It is important to recognize these inter-related factors when making, or helping others to make, decisions about care.

SOCIAL SUPPORT

Social support:

- is an important determinant of health throughout life
- influences an individual's outlook on the end of life - whether the remaining days are seen as a waiting period before death or as time left to continue living
- helps dying people find ways to say goodbye to all the things they have known, cherished and loved throughout their lives
- provides a connection with the past and may assist people to find meaning in their lives[9]

Seniors, particularly the very old, often have fewer social resources to draw on:

- They have likely felt the loss of friends and family members.
- Many do not have anyone at home to provide care or to support them.[10]
- Spouses are often frail and only able to provide limited assistance.[11]

Consequently, informal support is often limited, resulting in dependence on the formal system for social support. Staff members and volunteers often attempt to fulfill this need, but they can be limited in the amount of support they can provide.[12]

Although it is important that social support be available, the dying person may exhibit withdrawal from family and friends. Withdrawal can result from a more or less deliberate decision to disengage from social life as death draws near, possibly to focus on intrapsychic or spiritual concerns. Increasing fatigue as the illness progresses may also limit the person's capacity to maintain relationships. Social withdrawal, however, can also be a sign of distress. For instance, if seniors are embarrassed by their appearance or disability or are experiencing clinical depression, they may shun the presence of others.

What Can You Do to Encourage Social Support for Seniors at the End of Life?

Health Care and Social Service Providers:

- Encourage families and friends in their supportive role by reinforcing their value to the dying person.
- Provide opportunities for socialization with family and friends but do not assume that socialization is desired.
- Determine why family members/friends may be withdrawing (e.g., fears, anxiety).

Families:

- Offer support and encourage others to provide support to your loved one while recognizing that he/she may be experiencing internal conflict about relationships. For example, he/she may fear that his/her condition will have a negative impact on others, yet want to spend time with family and friends more than ever.[13]

CHALLENGES RELATED TO DYING WELL

ISOLATION

Isolation during the last phase of life can result from a loss in social or familial role, frequent hospitalizations and restrictions due to the illness.

How can isolation occur?

- Dying at home can be isolating if people in the social network are not fully aware of the suffering endured by the dying person and the family at home, which results in less support at a time when it may be greatly needed.[14]
- Withholding discussion of their experience due to a fear of alienating others or appearing to lose hope can create emotional isolation for people who are dying.
- Withholding information from seniors about their condition also isolates them, denies them control over decision-making and places barriers between seniors and the health care and/or social service providers.[15]
- Dying in a long-term care facility or in a hospital can also separate seniors from others.

The reality of dying can be overwhelming - no one else can fully understand its impact or significance for the individual. The knowledge that one ultimately dies alone can be very disconcerting and can result in an overwhelming sense of loneliness.

What Can You Do to Reduce Isolation of Seniors at the End of Life?

Health Care and Social Service Providers:

- Provide information about, and encourage the use of, community resources as appropriate to reduce isolation, such as volunteer programs and day hospices.

Families:

- Reassure your loved one of his/her continuing importance to the family and the community.[16]
- Encourage all family members, including the dying person, to discuss their experience, hopes and fears.

MARGINALIZATION

The majority of deaths in Canada take place in acute care hospitals. End-of-life care resources are often concentrated on younger cancer patients, resulting in the marginalization of older people who are dying in hospitals and long-term care facilities.[17]

When a senior is dying but has not been referred to a palliative care program, the individual may not receive appropriate services. This can happen because the person may have multiple health problems and while he/she could die from any one of them at any time, there may not be one specific illness that threatens his/her life.

- Seniors with dementia rarely receive palliative care. Even though their prognosis is poor and they have significant health problems associated with the condition, only a small proportion of persons receiving palliative care have a primary diagnosis of Alzheimer disease. Aggressive medical treatment is usually not prescribed and health care and social service providers may fail to recognize and treat pain appropriately, resulting in unnecessary suffering.
- Seniors who are dying of congestive heart failure and certain respiratory diseases also rarely receive palliative care services even though they suffer from incurable illnesses, painful symptoms, an illness trajectory that leads to death and also have the need for psycho-social and spiritual support.[18]

What Can You Do to Reduce Marginalization of Seniors at the End of Life?

Health Care and Social Service Providers:

- Aim to provide all dying patients with the same quality of care regardless of care setting, while understanding the particular needs of different population groups.

Families:

- Ensure that your loved one receives appropriate care. Communicate often with health care and social service providers to ensure that your family's needs are clearly understood.

FEARS AND CONCERNS

Seniors want to feel safe and to be treated with compassion and dignity.[19] There are many fears and concerns that can inhibit this feeling of safety. Fears and concerns are influenced by culture, degree of social support, knowledge of the illness and past experience. Unfortunately, the fears and concerns of seniors are sometimes discounted as they have already lived long lives and therefore should not fear death.[20]

Seniors tend to think about death more than younger people due to the multiple losses that they experience and they tend to accept death more than younger people.[21] However, it should not be generally assumed that seniors do not fear death. It is important to recognize real and potential fears to address them in a timely manner. What are common fears and concerns of seniors?

- losing their independence
- becoming a burden[22]
- losing control due to physical or mental deterioration[23]
- choking or suffocating, sensory loss, paralysis and the inability to communicate
- fearing that the pain will not be relieved; or that they will be overly sedated[24]
- being easily forgotten
- suffering with indignity[25]
- losing one's self and the grieving process that accompanies it[26]
- dying alone or without anyone caring. This is particularly true for seniors who have outlived their friends, disengaged from community life, and who are geographically distant from their families.[27]

In general, older Canadians tend to value quality rather than the quantity of their remaining life. Advance Directives, commonly referred to as living wills, are important in upholding these quality of life values. An Advance Directive:

- asserts a person's right to make decisions about health care treatment even when decision-making capacity no longer exists
- offers comfort to the dying person to know that caregivers are aware of their preferences and will honour their decisions even when they are no longer able to express them[28]
- helps to ensure that the patient's comfort and dignity are respected
- creates the opportunity for meaningful dialogue at the end of life
- helps to avoid disagreements about treatment among family members

Many people do not complete an Advance Directive. This may be because those who are dying may worry that their family will misinterpret the intent of an Advance Directive as a sign of distrust.[29]

People who overcome their fear of death tend to find meaning and purpose in the time they have left, feel more control over their lives and are more satisfied.[30] Little is known regarding the coping strategies that seniors use to address their fears and concerns. Some coping skills that have been reported by seniors include social support, prayer and internal self-control.[31] In addition to anti-anxiety medication, the following are effective methods of relieving fears:

- education regarding what to expect, what the treatment will be, "what to do if..." scenarios
- distraction (e.g., conversation)
- deep breathing, prayer, meditation and visualization
- reassurance[32]

What Can You Do to Reduce the Fears of Seniors at the End of Life?

Health Care and Social Service Providers and Families:

- Provide a comforting atmosphere.
- Pay close attention to the senior's psychological needs in order to prevent despair, loneliness and fear.[33]
- Help seniors, if they wish, confront their fears through open communication.[34]
- Respect the individual's fears and concerns. Alleviate fears when possible through open and constant communication.
- Educate the senior and family members about what to expect throughout the illness and the dying process.
- Encourage the use of Advance Directives. Do not limit seniors to a form - give them the opportunity to be clear about their wishes. Encourage people to talk about what is really important to them.[35]
- Pay attention to the seniors' ways of coping with fears and support their coping strategies.
- Respect the senior's individuality and ensure that their self-esteem is not compromised in any way.
- Reassure the senior that he/she will not be abandoned by the health care and social service team.

FINDING MEANING AND PERSONAL GROWTH

When people feel their lives have meaning or importance to others, they face death with a greater sense of calmness. Of course, the meaning of the dying experience will vary dramatically between individuals: some deny it, some accept it, and some embrace it.[36] Dying offers important opportunities for growth, intimacy, reconciliation and closure in relationships.[37] The inevitable changes in roles and responsibilities within relationships can have significant meaning for seniors.[38]

- A strong sense of life meaning helps seniors to cope with crises and is associated with a greater sense of control and lower levels of depression when health deteriorates. Spiritual support and guidance may be essential when people face crises that challenge their will to live and their spiritual beliefs. This does not necessarily have to come from a religious leader; rather any sensitive person can provide spiritual support.[39]
- The expression of spirituality may vary depending on ethnicity, gender, social class, personal experience and cohort.[40]

The majority of seniors come to terms with their mortality. In particular, many seniors experience an increased "awareness of finitude" as they age and see many of their peers dying.[41] This "awareness" initiates the following processes which reduce anxiety and increase acceptance of death:

- "Legitimation of biography": Awareness that one is living through the last stages of an autobiography and that time is limited. This stage is marked by an increased preoccupation with identity and a focus on the past, rather than the future.
- "Legitimation of death": Seniors want the last chapter of life to be good. They want to maintain control, independence and not to become a burden.
- "Authorship": Emphasizes the need for control over the end of life.

"The application of the principles of palliative care, which offer awareness, truth-telling, pain relief, and social and spiritual support may do a great deal to increase the likelihood that seniors will have good endings and be in control during the final phases of their lives".[42]

During the end of life, life review and reminiscing are important tools for achieving meaning and control.

- Life review involves coming to terms with the meaning of one's own life and relationships with others. This is a normal developmental task of later life and is characterized by the return of memories about past conflicts. Life review can result in the resolution of conflicts and forgiveness.[43]
- Reminiscing involves remembering certain aspects of one's life that were important or meaningful and transmitting the lessons learned from experience.

Although these two processes are important, seniors are not always given the same opportunity to work through their feelings about death as younger people.[44] Life review and reminiscence can help seniors to consider what the dying experience means to them in the context of their past life and what it will mean to those left behind. These processes can also help seniors to make sense of their current situation and possibly to feel more comfort.

What Can You Do to Help Seniors Find Meaning and Personal Growth at the End of Life?

Health Care and Social Service Providers and Families:

- Encourage opportunities for life review and reminiscence. Do not be concerned if the older person seems to be "living in the past".
- Encourage expression of true feelings, dreams, fears, hopes, desires and expectations.
- Listen to seniors when they express a need to find meaning in their experience and answer concerns in the terms with which you feel most comfortable.[45]
- Empower seniors to be the authors of their lives to the end. Provide them with the assistance they need to make their endings good.[46]

> *"We have learned that dying is an integral and fundamentally human stage of living, and that when physical and emotional needs are sensitively met, the journey toward death - though always difficult - can be a rich and profound experience that gives meaning and completeness to life."*[47]

LOSS OF CONTROL

Loss of control is a predominant fear among many dying seniors. At a time when many uncontrollable changes are occurring, it is important for seniors to maintain control over the areas that are still manageable. Competent seniors can maintain control over major decisions such as choice of treatments, quality of life and resuscitation decisions, as long as they are adequately informed about the condition and proposed treatments.[48] This can involve appointing a substitute decision-maker and/or completing an Advance Directive. Less complicated areas of control can involve respecting tastes, preferences and lifestyle choices such as meals, scheduling and roles of caregivers. The way we approach everything we do with a senior can promote or take away control; it is important to be aware of this at all times.

- As a health care and social service provider, it is important to understand the senior's values. If the older person has learned unquestioned obedience to those in the medical profession, as many older generations have, he/she may be hesitant to ask about alternative treatments, voice concerns, or even ask questions. The provider should facilitate communication by encouraging discussion about the various treatment options and by emphasizing, when appropriate, input into decisions about his/her care.
- Cultural norms can affect decision-making as well: Some cultures do not promote individualism or autonomous decision-making and therefore the dying senior leaves decisions in the hands of others.

- It is important to note, too, that if seniors choose to make decisions, they might make decisions which are not in their own best interest, but are rather to protect family from emotional or financial pressures that may occur as a result of the illness.[49]

What Can You Do to Help Seniors Maintain a Sense of Control at the End of Life?

Health Care and Social Service Providers:

- Always ask permission to do something, respect freedom of choice, encourage seniors to make difficult decisions, and follow through with their choices and your commitments.[50]
- Recognize and respect the patient's values and choices which guide the decision-making process.[51]
- Encourage an open dialogue by inviting questions and opinions.
- Facilitate discussion between family members on health care decisions. Often, families are not sure how to initiate this type of conversation. Discuss specific situations or scenarios to obtain an accurate picture of the dying person's wishes. Allow private time with family and visitors as frequently as possible to facilitate these meaningful discussions.[52]
- Include competent individuals in discussions about their care, even when communication is difficult.[53]

Families:

- Encourage your loved one to think about and discuss his/her preferences for end-of-life care.[54] Decision-making guides such as "My Plans for Me", developed by Canadian Pensioners Concerned, are helpful tools. By discussing what is important to the dying person, substitute decision makers will feel more confident in their important role and your loved one will feel reassured.[55]
- Leave as much control in the dying person's hands for as long as possible.[56]

> *"We have learned that everyone faces death in his or her own way. Retaining the power of individual choice - about medical treatments, about the care setting, about practical, emotional, and spiritual services - is essential. Exercising choice preserves dignity and prevents isolation from the daily business of living."* [57]

FINANCES*

Financial considerations are important for seniors. Generally, seniors are more likely to live alone and to have a lower household income. Financial worries are associated with heightened distress and are an additional element of suffering for both the dying person and his/her family.[58] As well, during this time when resources are already stretched, caregivers often need to adjust their employment situation, resulting in a loss of family income.[59]

There can be many additional health care expenses at the end of life, particularly for lengthy and multi-systemic illnesses. Economic hardships on the family can affect the individual's choices for care. For example, the out-of-pocket expenses for drugs and services associated with care outside of the hospital can be an incentive to die in the hospital, which may not be the individual's preferred setting.[60] In the home, financial strains can cause a reluctance to pay for equipment or services which would alleviate pain and suffering.[61]

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* Additional information on this topic is in Chapter 6.

What Can You Do to Help Seniors with Financial Issues at the End of Life?

Health Care and Social Service Providers:

- Provide complete information about options and costs, including the consequences related to the options and costs, considering that financial pressures greatly influence decision-making and choices for care.
- Provide information and referral on insured services, community resources that provide services at minimal cost, financial advisors, and/or employee assistance programs.

Families:

- Explore all options and available resources within your family and through other avenues of support.

VULNERABILITY TO ABUSE AND NEGLECT

Poor health, increasing dependency on others, isolation and caregiver burden are factors that can lead to an increased vulnerability to abuse and neglect at the hands of caregivers.[62] Often, families are under pressure to take on numerous caregiving responsibilities without adequate support, personal resources, or confidence which results in a feeling of burden.

- If the family member is giving care out of obligation or coercion, the relationship with the dying person can be negatively affected.
- Resentment about being forced into an unfamiliar or unwanted role and guilt about this resentment are conflicting feelings that may exist within the caregiver or the senior.
- Resentment can also occur if the caregiver has experienced a loss in income or employment due to their responsibilities.[63]
- Many caregivers are also seniors and frail themselves, therefore multiplying the strain of caregiving.
- Lack of skill at providing care may lead to poor and/or abusive care.
- The main situational factor related to abuse is isolation, either deliberate on the part of the abuser or due to illness-related mobility restrictions.
- Deliberate isolation tends to occur slowly and inconspicuously, for example when family members and friends are told by the abuser that their visits are neither necessary nor welcome.
- Seniors from minority and immigrant groups may be particularly vulnerable to abuse. Factors that may contribute to the potential for abuse include the loss of traditional support systems, language barriers which isolate them, increased dependency on younger family members and the decline of stature in the family.[64]
- Seniors can also suffer abuse from health care and social service providers, particularly in institutions where care is generally scheduled for the convenience of staff, rather than for the patients:
- Many institutions do not have adequate resources to provide effective end-of-life care which results in unmet needs and undue suffering.
- Some policies and practices within institutions, including visiting hours and lack of privacy for couples, contribute to the isolation of the dying person.
- Inappropriate use of restraints, chemical or physical, is an abusive practice that contributes to loss of dignity.

While most caregivers have positive attitudes towards their loved ones and wish to provide the best support possible within a caring environment, this is not true in every family.[65]

Financial abuse

The most common form of abuse occurs when seniors lose part or all of their savings or are pressured to relinquish the management of their money to another person. It is important to keep in mind that due to pride, family loyalty, a high degree of dependence on caregivers or their value system, some seniors may be reluctant to report abuse. They may feel helpless and overwhelmed or fear abandonment.

Signs to Watch for in Abuse and Neglect:

Characteristics of potential abusers:[66]

- a need for control
- exhaustion
- lack of patience
- financial problems
- low self-esteem and a lack of self-respect
- poor social skills
- resentment towards the victim
- ageist attitude - misinformed about the aging process and natural age-related changes

Circumstances conducive to abusive behaviour:[67]

- alcohol or substance abuse
- financial hardship
- a history of abusive family relationships
- lack of communication or agreement among family members about care
- lack of support in the community
- isolation - geographical or social
- dependency (of the older adult on the caregiver or of the caregiver on the older adult)
- caregiving responsibilities assumed out of obligation or guilt
- lack of caregiver recognition

Signs of abuse can include, but are not limited to:

- unexplained injuries in various stages of healing, grip marks
- delay in seeking treatment
- withdrawal, low self-esteem, extreme passivity, apathy, anxiety in the presence of the caregiver
- reluctance to participate in decision-making, makes excuses for social isolation
- unexplained discrepancy between income and standard of living, overdrawn or lower than expected bank balance
- malnourishment, dehydration, absence of aids such as dentures and glasses, unwarranted use of restraints
- lack of attention to personal hygiene[68]

Caregiver characteristics that may require further assessment include:

- excessively concerned or unconcerned
- treats the senior like a child
- has minimal eye contact with the senior or the health care and social service provider
- blames the senior

- responds defensively when questioned
- reluctant to allow the older person to be seen alone or obstructs access to treatment
- exhibits aggressive gestures

Detection of Abuse

Detection of abuse and neglect of seniors is sometimes difficult because it depends on indicators that may be difficult to isolate from the normal aging process or due to the illness. For example:

- bruising can be a side effect of medication, due to fragile tissue caused by aging, or as a result of a fall
- fractures may be caused by osteoporosis
- loss of money or possessions may be due to dementia[69]

At the same time, there may be cases of abuse where the standard indicators are not evident. Health care and social service providers need to be sensitive to changes in their client's relationships, physical status and emotional state and trust their instincts.[70]

What Can You Do to Prevent Abuse and Neglect of Seniors at the End of Life?

Health Care and Social Service Providers:

- Be aware of the signs of abuse and address them immediately.
- Monitor the caregiver's stress level and perceived burden, in order to anticipate potentially abusive situations and provide timely intervention (e.g., respite).
- Provide information to the senior about community services such as support groups. Use innovative and culturally appropriate ways to reach ethnic seniors and those with low literacy levels.
- Maintain contact with vulnerable, isolated seniors through informal yet fairly regular contact, such as letter carriers or neighbours. Programs such as Friendly Visiting, Telephone Assurance and Letter Carrier Alert are important in reducing the risk, especially in rural areas where seniors can be isolated for extended periods of time.[71]
- Ensure family caregivers understand the senior's situation and needs for care.

Families:

- Recognize the signs of burnout in yourself and others. Make a conscious effort to stay healthy.
- Confront any negative feelings you may be experiencing and find appropriate ways to deal with them.
- Seek resources and supports from your community and from professionals to assist you in providing care and in caring for yourself.

EFFECTIVE CARE DELIVERY MECHANISMS*

The needs of seniors who are dying are complex and require attention from interdisciplinary teams. A collaborative effort between health care and social service providers, community organizations, volunteers and families and friends is fundamental to meeting the total requirements and challenges of caring for seniors who are dying.[72]

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* Additional information on this topic is in Chapter 3.

End-of-life care for seniors requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to, and including, the period of bereavement.

Effective care delivery responds in a timely manner to the individual's changing needs and expectations.[73]

Important Elements of an Effective Care Delivery Mechanism for Patient-Centred Care:

- interdisciplinary, coordinated teams skilled in palliative and geriatric care with a high degree of communication between all players
- service coordination, with an appointed coordinator/advocate, across the health continuum. The continuum may begin with care by a family physician, continue with acute care in hospital, and then move to long-term care or community care in a home or hospice. Clear methods of communication among all the players must exist. Clearly defined linkages and accountability among all the players are essential to providing consistent, cost-effective and competent care.[74]
- continuity of care from skilled health care and social service providers
- care at the appropriate time and place including 24 hour, seven day a week service
- holistic care that is responsive to the senior's and family's needs; considers their personal, cultural and religious values, beliefs and practices as well as their physical, psychological, social and spiritual expectations
- concern for quality of life, including symptom control and pain management
- normalcy; encourages the senior to live as normally as possible despite his/her illness
- bereavement counselling and respite services
- volunteer program that screens, trains, monitors and evaluates its valuable unpaid workforce
- opportunities for meaningful activity and connection with family
- regular evaluation of programs and services
- continuing education and a support network for staff members
- supportive and non-restrictive organizational policies
- advice and assistance to families on caring for their loved one
- adequate physical space, human resources and equipment to provide effective care[75]

When evaluating a care delivery mechanism, the Canadian Palliative Care Association suggests using this guiding question:
Does the system focus on being responsive to the expectations, needs and preferences of patients and families in order to improve their outcomes within the limits of available resources?

Success or failure of the program is ultimately determined by the senior and family's satisfaction with the care received. This is a shift from the traditional method of evaluation which involves an assessment of how well the professional team has followed through with the care plan.

The acute care medical model, which emphasizes cure versus pain relief, often does not fully meet the needs of dying seniors.[76] In this model, death is often seen as defeat by the medical community.[77] This view of "death as defeat" must be challenged in order to promote effective end-of-life care.

There are a variety of locations in which a person can receive end-of-life care including home, hospital, long-term care facilities and hospices. Each option has benefits and drawbacks that must be weighed carefully by the senior and his/her family. The ideal setting for care may vary as the senior's needs change.[78]

Approximately one-third of Canadian seniors die at home. Most people hope to die at home for reasons such as the ability to maintain a close connection with their families, to live as normally as possible and to have a greater sense of control.[79] Unfortunately, for financial reasons and other psychosocial factors, few frail seniors in the community have the necessary resources to die at home with dignity. Some may hold a romanticized view of dying at home that can be quickly shattered when the realities of the intensive, 24-hour care requirements surface. Frail seniors and their caregivers may be unprepared for and overwhelmed by the symptoms that accompany dying. This may be why many people who intend to die at home end up in the hospital setting.[80]

MYTH: DYING AT HOME = DEATH WITH DIGNITY

Regardless of the setting in which care is provided, the philosophy and principles of hospice palliative care must be extended to the care of seniors.* In particular, this must become an integral part of care in long-term care facilities.[81]

VOLUNTEERS

Trained volunteers are an essential part of most palliative care programs because they complement and enhance professional care.[82]

They:

- play a valuable role in addressing the social and emotional needs of the senior who is terminally ill[83]
- provide support services to seniors and families such as companionship, caregiver relief, transportation and bereavement support[84]
- provide a link between health care and social service providers and seniors and can help the family through their grief process

CULTURE

It is often a challenge, in a multicultural society like Canada, to provide culturally appropriate care. The values and practices of seniors may differ from those of their caregivers and this may result in conflict. Cultural differences can manifest in attitudes towards pain, life, death, family care and outside help; expressions of grief; and bereavement practices.[85] It is important that the care provider understands the important influence of culture in dying and grieving.†

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* Additional information on this topic is in Chapter 5.

† Additional information on this topic is in Chapter 8.

What Can You Do to Help Seniors Choose the Most Appropriate Setting for Care at the End of Life?

Health Care and Social Service Providers:

- Ensure that patients and families are fully informed about the benefits and limitations of each care setting, so that they can choose the one that will best suit their needs and circumstances.

Families:

- Consider your loved one's preferences and the family's ability and resources to provide support in different settings when making decisions about care.

For one family, quality care for their father meant making the commitment to care for him at home throughout his illness. They were able to do that with support from visiting nurses, homecare workers and hospice palliative care volunteers. As he battles terminal cancer, his medical needs are met by experts, his family provides round-the-clock comfort and family friends drop in regularly. The family, though stretched to the limit, can manage because of the support and respite.

For one woman, quality care meant choosing to live and receive treatment in hospital, cared for by palliative care specialists and supported by extended family. For as long as possible, she made regular visits to her home to spend time with her husband and children. She felt this arrangement protected her family from the distress of her most acute symptoms and treatments.[86]

LIMITATIONS IN SERVICE DELIVERY

Adherence to a "patient-centred approach" is optimal; however, evaluation of the quality of care in one setting over another is difficult as the pattern of care inevitably varies with each patient, depending on individual needs.[87] There is a need for further research on optimal approaches to end-of-life care for seniors.[88]

One limitation in service delivery is that payment for services is often influenced by the setting in which it is provided. For example, services or equipment funded in hospital may not be available at home or in a hospice setting. Also, the eligibility criteria and range of services available vary within and between jurisdictions.[89] Home care needs are difficult to meet without supportive, healthy family caregivers whose efforts can be supported by home care services.[90]

In general, limitations in service delivery include the following:

- in-service training
- funding
- accessibility
- lack of a standard approach to assessment and practice
- legislation
- coordinated approaches
- research

As mentioned in Chapter One, many seniors do not receive a "palliative" diagnosis due to the complicated process of diagnosis for older persons with multiple symptoms and diseases. Often, a diagnosis occurs through exclusion, once attempts at therapy and rehabilitation have failed.[91] This means that a "palliative" diagnosis can be obtained late in the dying trajectory, which leaves limited time in the continuum of care.[92] On the other hand, some may receive end-of-life care for a long period of time. Patients and families benefit most from palliative care when it is offered in a timely manner. In order to provide good end-of-life care, it is helpful if a relationship between health care and social service providers, volunteers and the dying person is established prior to the end stages of the disease.[93]

What Can Be Done to Promote Excellent End-of-Life Care for Seniors?

Health Care System:

- Increase resources for end-of-life care.
- Form close links between end-of-life care and long-term health care and social service providers so that those who live in institutions are not overlooked.[94]
- Ensure flexible eligibility criteria for services in order to accommodate those who have an obvious need for end-of-life care but who do not have a palliative diagnosis.
- Offer end-of-life services in a timely manner.
- Ensure that all health care and social service providers receive culturally sensitive education and training on end-of-life issues and the unique needs of seniors who are dying.

CONCLUSION

Respect for values, ongoing communication and an interdisciplinary, holistic approach are key elements of quality end-of-life care, regardless of where the care is provided. Seniors and their families should be fully informed about the condition, prognosis and range of options for care.

Some deaths can be quick and unexpected. Providing quality end-of-life care is often not an easy task. Enormous challenges arise even in the most supportive environments; however, the experience as a whole can be extremely rewarding. A good death can be a positive life experience for everyone involved.

> *"We have learned that living with life-threatening illness is tough, demanding and intense for loved ones as well as the patient. But with practical, emotional, and spiritual support though all the stages of illness and bereavement, loved ones can also experience privileged moments of special communication, growth, and even joy. Such moments can be a shared gift."*[95]

SUMMARY RECOMMENDATIONS FOR PRACTICE

- Respect seniors as unique individuals with particular beliefs, values and preferences.
- Facilitate open and timely discussion of decisions related to treatment, care, and planning for families, preparing wills and other issues of significance to seniors.
- Provide information about ways of minimizing the financial burdens of end-of-life care.
- Encourage families and friends in their supportive role and provide opportunities for socialization.
- Encourage the use of resources that can help reduce feelings of isolation.
- Respond sensitively to seniors' pain, fears and anxieties.
- Encourage opportunities for life review and reminiscence.

- Respect seniors' need for control and independence.
- Observe for, and respond to, signs of burnout in family caregivers.

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MAINTAINING COMFORT

INTRODUCTION

The primary goal of this chapter is to provide an approach to managing common distressing symptoms in the end-of-life care for seniors. Dosing suggestions refer to initial therapy and should be titrated according to individual response. Readers are cautioned that therapies and clinical recommendations in geriatrics and palliative care are constantly evolving. This chapter is intended for reference only and does not replace the discretion and judgement of individual caregivers in the care of seniors. Complementary therapies listed are those that are sometimes used for symptom management. As a comprehensive discussion of complementary therapy is beyond the scope of this chapter, readers should refer to other sources for more information.

SYMPTOM MANAGEMENT

Definitions

Symptom[1]

- A physical or mental phenomenon, circumstance or change of condition arising from and accompanying a disorder
- Specifically a subjective indicator as perceived by the individual

Many seniors have multiple chronic disease states, which can cause numerous distressing physical symptoms. These chronic diseases (eg., CHF, COPD, etc) do not have curative treatments and the goal of therapy is symptom management. Many symptoms are often not reported to caregivers and, when they are, they are frequently undertreated. Symptom assessment in older individuals can be complicated by cognitive impairment and communication difficulties. The following tables indicate the prevalence of symptoms among a group of individuals during the last year of life.

Prevalence of Symptoms in Patients with Progressive Illnesses Other Than Cancer*

SYMPTOM	PATIENTS EXPERIENCING SYMPTOM (%)
Pain	67
Dyspnea	49
Confusion/delirium	38
Anorexia	38
Depression	36
Constipation	32
Nausea/vomiting	27
Anxiety	25
Pressure sores	14

*Adapted from reference 4

Prevalence of Symptoms in Persons with Cancer*

SYMPTOM	PATIENTS EXPERIENCING SYMPTOM (%)
Pain	55-92%
Anorexia	31-79%
Nausea/vomiting	12-57%
Constipation	31-50%
Dyspnea	17-90%
Depression	46-56%
Confusion/delirium	24-52%
Pressure sores	28%
Anxiety	21-56%

SYMPTOM ASSESSMENT

Because symptoms are subjective, patient self-report must be the primary source of information. Many seniors are reluctant to report their symptoms as they do not wish to be viewed as "complainers", or they are fearful of what their symptoms may represent or of the medications that may be used to treat symptoms. As seniors may use indirect or non-specific terms to describe their symptoms, it is important that health care and social service providers listen carefully and be conscious of the non-specific manner in which seniors may describe their symptoms (e.g., pain may described as discomfort or soreness, nausea as stomach upset or queasiness).

Symptom assessments should occur at regular intervals following initiation of treatment, to follow the effectiveness of the treatment plan and upon a new report of symptoms.

The assessment of symptoms consists of the following steps:

- Identify the cause of the symptom
- Measure the quality and intensity of the symptom
- Recognize and assess the multi-dimensional aspects of the symptom†
    - Physical – including impact on functional ability
    - Psychosocial (psychological distress, use of alcohol and other non-medical drugs, cognitive status, previous history of depression, coping patterns with previous life stressors)
    - Cultural
    - Spiritual

There are a number of assessment tools available. Many clinicians find the assessment tools used by The Edmonton Palliative Care Program to be useful, user friendly and cover the multi-dimensional aspects of symptoms at the end of life. The instruments used by this group include the Edmonton Symptom Assessment Scale, CAGE Questionnaire, Mini-Mental State Questionnaire, and the Edmonton Functional Assessment Tool. The Edmonton Discomfort Assessment Tool can be used for seniors who are unresponsive or have communication difficulties. They can be downloaded from the Edmonton Palliative Care Program web site at www.palliative.org

PRINCIPLES FOR MEDICATION USE IN SENIORS AT END OF LIFE

Seniors experience the same distressing symptoms at the end of life as younger individuals and they deserve the

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* Information from references 1-3

† Additional information on this topic is in Chapters 2, 6 and 8.

same attention paid to these symptoms. Medications are an important component of symptom relief. When the issues discussed below are appreciated, medications can safely provide the desired effect of improving symptoms while minimizing the risk of adverse effects.

Seniors consume more medications as they tend to have more illnesses and medical conditions than younger adults. In general, the risk of medication-related adverse effects is increased among seniors. Factors contributing to this increased risk are age-related physiologic changes that can affect the elimination of medications by the kidney and liver. In addition, seniors may be more sensitive to the central nervous system effects of certain medications. The risk for adverse effects and drug interactions also increases as the number of medications increase. At the end of life, the disease process can compound these factors, further increasing the risk of adverse drug reactions.

The Canadian Medical Association has outlined the following principles for medication use in seniors.[3] While these principles are intended for the senior population in general, they are applicable to medication use at the end of life.[4] The key components of these recommendations are as follows:

- Know the senior

Know the specific diagnosis and the symptom being treated before using medication. Be aware of all the medications that the senior is taking. These include all prescription medication, over-the-counter products and any herbal, homeopathic or naturopathic agents. Health care and social service providers should assume that complementary therapies are being used and inquire about them as part of the routine assessment. It is also important to know the history of non-medical drugs such as alcohol, tobacco and caffeine. Monitor seniors on a regular basis for the development of adverse drug reactions. In particular, pay attention to cognitive status and be aware of the potential for delirium.

- Establish treatment goals

With the senior and his/her family, establish treatment goals for symptom management and determine how achievement of those goals will be established. Regularly assess the adequacy of response and review goals.

- Know the drugs

In general, start with low doses and titrate upwards based on response and the emergence of adverse effects. Whenever possible, minimize the number of medications, avoid duplication and complicated dosing regimens to reduce the risk of adverse effects, drug interactions and improve adherence. Conduct regular medication reviews and discontinue medications if appropriate. If the senior is residing in the community and he/she or a family caregiver is responsible for medication administration, verify that they understand the directions for the medication. Encourage the use of compliance aids.

One of the most important barriers to good symptom control is the reluctance to take medication because of fears of addiction, tolerance and that medications will hasten death. This is particularly true when opioids are being used. Provide ongoing education about these issues. When appropriate, ask other health care and social service providers to assist in providing this education.

- Consider the use of nonpharmacologic therapy

Many nonpharmacologic therapies offered by trained personnel (art therapy, music therapy, occupational therapy, physiotherapy, relaxation techniques and TENS) can be used with medications to improve symptoms such as anxiety, asthenia or pain.[5-10]

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ANXIETY

Presentation[1-4]

Anxiety may present in a number of ways, including agitation or restlessness, chest pain or discomfort, complaints of heartburn, a choking sensation, sensation of shortness of breath or smothering, diarrhea, dizziness or lightheadedness, insomnia. Signs include sweating, tachycardia and tremor or shaking.

Causes[1-4]

Anxiety is often a comorbid disorder that is associated with pyschosocial issues such as lack of family or caregiver support, fear of dying, fear of being a burden to loved ones, and financial concerns. Frequently associated physical conditions include respiratory disease with dyspnea, cardiovascular disease, chronic pain, delirium, dementia and depression. It is important to point out that depression sometimes presents as anxiety.

Other precipitating factors are medication effects, especially in the terminal phase of illness. Caregivers may also use less benzodiazepines and opioids if there is a decreased level of consciousness leading to withdrawal states which often present as agitation or anxiety. These may become clinically evident days later than might be expected in young, healthy adults. Withdrawal can also occur as the less alert individual reduces alcohol or nicotine consumption.

Approaches and Interventions[1-4]

It is important to provide reassurance and a familiar, safe environment. A psychosocial assessment should be conducted and support provided as appropriate.* Spiritual support may be helpful.† Nonpharmacologic therapies that can be considered include therapeutic touch, relaxation therapy, music therapy and art therapy. Other interventions are outlined below.

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* Additional information on this topic is in Chapter 2.
† Additional information on this topic is in Chapter 7.

PROBLEM	INTERVENTION
Anxiety	■ Manage unresolved symptoms - Pain - Dyspnea ■ Treat underlying depression if present ■ Manage delirium if present ■ Manage behavioural symptoms associated with dementia if present ■ Consider intermediate acting benzodiazepines if symptoms persist despite other interventions - Lorazepam - Initiate 0.25-0.5 mg po or sl or sc once daily to BID prn or regularly - Oxazepam - Initiate 7.5-15 mg po once daily to BID prn or regularly ■ Note: - Benzodiazepines can cause paradoxical reactions with increased agitation in some seniors - Generally avoid benzodiazepines with long half-lives for anxiety as their effect is prolonged in seniors - Diazepam, flurazepam, chlordiazepoxide

Complementary Therapies*

- Acupuncture
- Aromatherapy
- Biofeedback

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ANOREXIA/CACHEXIA/WEIGHT LOSS

Definitions

Anorexia[1]

- Decreased or complete loss of appetite

Cachexia[1]

- Also known as wasting
- Malnutrition characterized by clinically important weight loss
- Includes loss of both adipose tissue and muscle mass

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* Additional information on this topic is found in Chapter 8.

PRESENTATIONS

The presentation of anorexia and/or cachexia may include drowsiness, fatigue, lethargy, chronic nausea, loss of strength and energy, generalized weakness, asthenia and skin breakdown or chronic wounds.

CAUSES[1-9]

The anorexia-cachexia syndrome in seniors is associated with many disease processes including malignancy, cardiac disease, COPD, dementia, delirium, depression, untreated hyperthyroidism, and Parkinson's disease. Other factors that can cause or contribute to anorexia include dislike of institutional food or ethnic food preferences, oral complications (painful mouth sores, thrush, dry mouth, poorly fitting dentures), dysphagia or painful swallowing, taste disorders, nausea, vomiting and uncontrolled pain. Caregivers may sometimes not recognize that the senior requires assistance with feeding.

Medications can contribute to anorexia by causing nausea or dyspepsia (SSRIs, digoxin toxicity, NSAIDs), or by causing excess sedation or confusion (benzodiazepines, tricyclic antidepressants or neuroleptic agents).

APPROACHES AND INTERVENTIONS[1-13]

PROBLEM	INTERVENTION
Altered taste	■ If medication suspected, discontinue if possible ■ Choose foods that address preference for taste and texture ■ May wish to increase seasoning ■ Encourage fluid intake
Anorexia	■ Identify and treat underlying causes if appropriate (see depression, dementia, delirium, nausea/vomiting) ■ Encourage smaller, more frequent meals ■ Encourage individuals to eat when hungry and have food available when it is requested ■ Use a small plate to give the impression of having a complete meal ■ If medication suspected, discontinue or reduce dose if possible ■ Medications to stimulate appetite - Medications may produce an increase in appetite and small weight gain (mainly fat) but can be associated with adverse effects that may limit their use - **Evidence in frail seniors is limited** - These medications are recommended only for short-term use when other interventions have failed and individuals find anorexia and its associated weight loss particularly distressing - Individuals and their families should be counselled that while appetite may improve, weight gain may be minimal - Dexamethasone 1 to 4 mg daily - Megestrol acetate 80 mg BID to 160 mg TID for patients with cancer or up to 200 mg BID for frail seniors without malignancy (see drug table)

PROBLEM	INTERVENTION
Reduced nutritional intake or increased metabolic need (i.e., malignancy)	■ Determine if assistance with feeding is required ■ Consult dietician to assess dietary needs and preferences[1] - Identify food preferences and provide these to the individual - Caloric and protein requirements - Caloric and protein supplements if tolerated - Can be diluted in water or with ice chips

Medications used to treat anorexia[1, 9-13]

DRUG	DOSE RANGE	COMMENTS
Dexamethasone	1-4 mg daily	Increase in appetite may last only a few weeks May cause or contribute to: ■ Hyperglycemia ■ Oral candidiasis ■ Confusion ■ Electrolyte abnormalities ■ Myopathy
Megestrol acetate	Dosages of 160-480 mg per day found to increase appetite in persons with cancer but no significant weight gain[10,11] Dosages of 400 mg daily in residents of a long-term care facility found to improve appetite but associated with adverse effects that limit use[12]	May cause or contribute to: ■ Hyperglycemia ■ Edema ■ Confusion ■ Thrombo-embolic complications (i.e., DVT, PE) ■ Vaginal bleeding upon withdrawal

Complementary Therapies[9]

- Acupuncture
- Therapeutic touch
- Traditional Chinese medicine

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CONSTIPATION

Definitions

Acute constipation

- No or inadequate bowel movement for three or more days[1]

Presentation

The signs and symptoms of constipation include a reduced number or no bowel movements with increased stool consistency, flatulence, bloating, or a feeling of incomplete evacuation following a bowel movement. Constipation also sometimes presents as overflow diarrhea in the presence of fecal impaction. It may be associated with anorexia, nausea and vomiting and confusion.

Causes[2,3]

- Disease effects
  - Confusion
  - Immobility
  - Poor dietary intake
  - Poor liquid intake
  - Weakness
  - Related to malignancy
    - Post-operative ileus
    - Intestinal obstruction
    - Spinal cord compression
    - Hypercalcemia
- Concurrent disease states
  - Hypothyroidism
  - Hypokalemia
  - Diabetes
  - Diverticular disease
- Anal/rectal pathology
  - Hemorrhoids
  - Anal fissure/stenosis
  - Superficial ulcerations
  - Pruritus
- Medications

- Opioids
- Iron
- Medications with anticholinergic effects
    - Tricyclic antidepressants
    - Phenothiazines
    - Carbamazepine

LAXATIVES	COMMENTS
Bulk-forming agents	
■ Psyllium	■ Can be used in chronic constipation if non-pharmacologic interventions do not produce results ■ Administer with meals and avoid bedtime administration ■ Must be given on a regular basis (not prn) ■ Avoid in the following situations: - Individuals receiving opioids or other constipating medications that alter peristalsis - Fluid intake is less than 1000 ml per day - Suspected impaction, ileus or bowel obstruction - Individuals at risk of aspiration
Stool softeners	
■ Docusate calcium capsule - Dosage: 240-480 mg/day ■ Docusate sodium liquid - Dosage: 200-400 mg/day	■ Useful for short-term use to avoid straining ■ Value of chronic use is unproven ■ High doses may cause anal leakage and excoriation of perianal tissue ■ Docusate sodium liquid is concentrated and has a very bitter taste. Dilute in juice if given by mouth. Dilution is not required if administered by NG or PEG tube. ■ Calcium and sodium content of preparations are clinically insignificant
■ Mineral Oil - Available in liquid or gel formulation - Dosage: 30 ml as required	■ Useful for short-term use if excessively hard stool or as initial treatment for impaction (follow-up with MOM and or enema may be required). ■ Avoid long-term use ■ Avoid in individuals at risk of aspiration (liquid or gel products) ■ Long-term use may cause anal leakage and excoriation of perianal tissue ■ Long-term use may reduce absorption of fat-soluble vitamins (i.e., vitamins A, D and E)

LAXATIVES	COMMENTS
Saline agents	
■ Magnesium hydroxide (MOM) liquid or tablets - Usual dosage: 15-30 ml or 4-8 tablets at bedtime - Larger dosages of 45-90 ml may be required for refractory, chronic constipation	■ Suitable for chronic use ■ May be administered regularly or on a prn basis ■ Avoid in individuals with renal failure due to high magnesium content: - Liquid- 41 mmol per 30 ml - Tablet- 5.3 mmol
■ Sodium phosphates - Dose for fecal impaction - 45 ml initially - may repeat in 5 hours if necessary - dilute in 120 ml sweet juice - follow by 240 ml of juice	■ Useful for management of fecal impaction ■ Extremely salty taste, so requires liberal dilution as described ■ High sodium content: - 434 mmol/90 ml (equivalent to 3L normal saline) ■ Due to high sodium content, avoid in following situations: - individuals requiring sodium restriction - individuals with congestive heart failure - individuals with congenital megacolon
■ PEG-lyte Lavage - Powder containing polyethehylene glycol 3350 NaSO4, NaH3O2, NaCl, KCl - Dose for fecal impaction - Administer 100-150 ml by mouth or NG tube every 30 minutes (i.e., 1-2 L over 3-4 hours) - Repeat next day if necessary - If dosage rate not tolerated, give smaller volumes less frequently ■ Can be given orally or via NG tube	■ Used for fecal impaction ■ Dosage rate often not tolerated if individual is very ill and/or frail ■ Negligible absorption of electrolytes ■ Very salty taste **Laxatives**

LAXATIVES	COMMENTS
Stimulant agents	
■ Direct stimulation of intestinal smooth muscle activity ■ Enhance secretion of water and electrolytes into bowel lumen	■ Stimulants as a class - are useful to manage acute constipation (if bowel obstruction is ruled out) - Useful for the prevention and management of opioid-induced constipation. Can be used in conjunction with other agents for this purpose. - Some individuals may complain of abdominal cramping. Decrease dose or switch to another stimulant agent.
■ Cascara Sagrada - Available as 300 mg tablet or fluid extract - Usual dose for tablet is 300-600 mg at bedtime - Usual dose for fluid extract is 5-10 ml at bedtime	
■ MOM + Cascara - Concentrated liquid - 15 ml is equivalent to 30 ml MOM + 5 ml cascara - Usual dose is 15 ml at bedtime	
■ Bisacodyl tablets - Usual dose is 5-10 mg at bedtime	■ Bisacodyl tablet is enteric-coated; avoid administration with MOM or antacids
■ Senna - Usual dose is 2-4 tablets at bedtime - Also available as senna tea	
Osmotic agents	
■ Lactulose - Usual dose 15-30 ml daily	■ Reserve for use in those individuals who have not responded to other laxatives
■ Sorbitol - Usual dose 15-30 ml daily	■ Very sweet taste. Can be diluted in juice or warm milk. ■ May cause some bloating and gas pains

LAXATIVES	COMMENTS
Suppositories	
■ Glycerin	■ Use glycerin suppository first, then bisacodyl suppository if glycerin fails
■ Bisacodyl 10 mg	■ Chronic, routine use may cause irritation of rectal mucosa
Enemas	
■ Sodium Phosphate	■ Enema should be pre-warmed in tap water ■ Requires retention of fluid until stool evacuation ■ Use proper administration to avoid abrasion of rectal wall ■ May repeat dose in 30 minutes if necessary ■ Frequent use may damage rectal mucosa
■ Mineral Oil Enema	■ Enema should be pre-warmed in tap water ■ Lubricates hard stool in the rectum ■ May follow in several hours with other measures

Approaches and Interventions

- General principles[3]
  - Establish the individual's normal bowel routine
    - Number of bowel movements per week
    - Consistency, colour and volume of stool
  - Encourage mobilization as tolerated
  - Ensure adequate hydration
  - Establish a regular toileting routine
    - Strongest peristalsis occurs in early morning after breakfast
  - Sit individual upright when toileting if tolerated
  - Provide as much privacy as possible
  - Maintain good peri-anal care
  - Use laxatives when necessary
  - Determine adherence with laxative regimen
    - Patient dislike is a common cause of noncompliance
      - Taste
      - Abdominal cramping

PROBLEM	INTERVENTION
Fecal impaction	■ Consider flat plate x-ray ■ Digital rectal exam to determine presence, amount and consistency of stool - Glycerin suppository - Sodium phosphate enema if suppository not effective in 30 minutes - Mineral oil enema if stool is very hard ■ If impaction - Sodium phosphate oral solution 45 ml po - high sodium content - do not use if sodium restriction, congestive heart failure or congenital megacolon - PEG-lyte lavage if unable to tolerate sodium load of sodium phosphate oral - 100 ml q30 minutes - smaller volumes less frequently if unable to tolerate dosing rate - if impaction in proximal colon, consider tap water enema
Prevention of opioid-induced constipation	■ Begin stimulant laxative when opioid initiated - Senna ■ If stool consistency if very hard, add stool softener to reduce straining ■ Prune juice if tolerated ■ Avoid bulk laxatives ■ Consider use of prokinetic agents - Domperidone, metoclopramide

Complementary Therapies[4]

- Homeopathy
    - Staphyagria for moderate constipation
    - Alumina for severe constipation

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DEPRESSION

Definitions[1]

- Depression is characterized by at least two weeks of depressed mood or loss of interest accompanied by other symptoms. It often presents atypically in older individuals
- Bereavement is a reaction to the death of a loved one that may produce similar symptoms but is not usually considered to be depression unless the symptoms last longer than two months after the loss.

Presentation[2]

Affective and behavioural symptoms may occur such as apathy, lack of enjoyment or pleasure with social withdrawal. Feelings of sadness, hopelessness, helplessness, guilt and worthlessness may be present. Somatic symptoms include agitation/restlessness, anorexia/weight loss, decreased energy, insomnia or hypersomnia, psychomotor retardation and somnolence. Confusion may also occur.

Depression is often associated with comorbid illness, chronic pain, chronic debilitating illness, dementia and medication effects

Diagnosis can be difficult as diagnostic criteria (see DSM-IV) rely on neuro-vegetative symptoms which frequently present in severe medical illness. Seniors often experience bereavement which may be difficult to distinguish from depression. Feelings of guilt and worthlessness may indicate depression rather than bereavement. There is also a need to differentiate sadness appropriate for the illness and the situation from clinical depression.

The following assessment instruments are useful for the senior population: Geriatric Depression Scale[3] if no cognitive impairment and Non-verbal Depression Scale[4] or Cornell Scale for Depression in Dementia[5] if cognitive impairment is present.

Approaches and Interventions[2,6,7]

PROBLEM	INTERVENTION
Bereavement	Listen to the individual and encourage him/her to express him/her feelings Assess and offer psychosocial support* Assess and offer bereavement counselling†
Sadness	Listen to the individual and encourage him/her to express him/her feelings Be nonjudgemental Legitimize the difficulty of the situation Provide reassurances of continued care and interest Respect the person's need to have hope Assess and offer psychosocial support+

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* Additional information on this topic is in Chapter 2.
† Additional information on this topic is in Chapter 6.
\+ Additional information on this topic is in Chapter 2.

PROBLEM	INTERVENTION
Clinical depression	■ Assess and offer psychosocial support * ■ Anti-depressant medication - Decision to use anti-depressant medication should consider the stage and context of the person and his/her illness - Generally takes several weeks to improve mood - Some agents may improve sleep and/or pain control in some individuals - Choice of medication will depend on previous response if past history of depression, presentation and side-effect profile - Start with low doses and titrate dose upwards to response - Tricyclic anti-depressants - Desipramine or nortriptyline generally have a more favourable side-effect profile - Amitriptyline, imipramine and doxepin exhibit higher anti-cholinergic activity - Initiate at 10-25 mg po once daily & titrate upwards by 10-25 mg every 7 –14 days - Usual maximum daily dose in seniors is 100 mg - If individual does not appear to be responding, check serum level - SSRIs - Use fluoxetine cautiously due to long half-life - Reserve for persons with past history of depression responding to fluoxetine (SSRIs do not exhibit class effect) - Initiate sertraline at 25-50 mg po daily & titrate to response by 25-50 mg every 7 –14 days (maximum daily dose 200 mg) - Most individuals respond to paroxetine 20 mg po daily (maximum daily dose of 40 mg if inadequate response to 20 mg daily) - Initiate fluvoxamine at 50 mg po daily & titrate to response by 50 mg every 7 –14 days (maximum daily dose 150-200 mg) - All SSRIs exhibit drug interactions, refer to appropriate drug interaction sources
Psychomotor retardation/ somnolence	■ Methylphenidate 2.5 mg po BID & titrate to response by 2.5 mg BID every other day (usual maximum daily dose 40 mg) - Do not use in those with hyperactive delirium or severe anxiety - Can cause confusion and hallucinations in some people - discontinue if this occurs - some clinicians suggest a test dose given in the am with assessment for adverse CNS effects at 2 hours - Avoid late afternoon & evening doses as can interfere with sleep - last dose given between 1200 and 1400 hours - Can be useful in the medically ill - Rapid but sometimes limited response

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* Additional information on this topic is in Chapter 2.

Complementary Therapies

- St. John's Wort
    - Do not use in conjunction with other anti-depressants due to potential drug interactions
    - May be of some benefit in persons with mild depression[8]
- Homeopathy

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DYSPNEA/BREATHLESSNESS/RESPIRATORY SYMPTOMS

Definitions[1-6]

Dyspnea/Breathlessness

- Laboured breathing that is accompanied by a sense of shortness of breath or suffocation

Presentation[1-6]

Shortness of breath may be accompanied by a feeling of being smothered or suffocated, anxiety, and difficulty in clearing secretions. Signs may include an increased respiratory rate (tachypnea), bronchospasm, use of accessory muscles and intercostal indrawing, and cyanosis. However, individuals may have minimal objective signs but experience severe shortness of breath. Verbal categorical (none, mild, moderate, severe) or visual analogue scale may be useful to assess the severity of distress.

Causes[1-5]

- Frequently multi-factorial
- Cardiac disease
    - Congestive heart failure with pulmonary edema
- Respiratory disease
    - Chronic obstructive pulmonary disease
    - Pleural Effusions
    - Pneumonia
    - Pneumothorax
    - Pulmonary embolism
    - Pulmonary fibrosis
    - Tumours (primary or secondary)
- Severe anemia
- Weakness/myopathy

Approaches and Interventions[1-11]

- Place the individual in Fowler's Position (semi-sitting position)
- Environmental modifications
  - Eliminate/reduce environmental irritants (e.g., cigarette smoke, perfumes, scents, etc.)
  - Keep room at comfortable temperature for the individual
  - Ensure adequate ventilation
    - Use fans
    - Open windows (avoid excessive cooling)
    - Keep a clear visual path between the individual and the fan or open window
  - Avoid overhydration
- Relaxation therapy for anxiety
- Therapeutic touch for anxiety

PROBLEM	INTERVENTION
Bronchospasm	■ Salbutamol 2-3 puffs q4-8h (with aerochamber) or 2.5-5.0 mg diluted to 3-4 ml with saline q4-8h via nebulizer ■ Can add ipratropium bromide 2-3 puffs q4-8h (with areochamber) or 250-500 ug (can mix with salbutamol) q4-8h via nebulizer ■ Steroids - Prednisone 10-50 mg po once daily
Cough	■ Cough suppressants - Dextromethorphan 15-45 mg po q4h prn - Codeine 10-15 mg po or 5-7.5 mg sc q4h prn - Hydrocodone 2.5-5mg po q4-6h prn - Morphine 2.5-5mg po or 1-2.5 mg sc q4h prn
Hypoxia	■ Oxygen if O_2 saturation less than 90% - Monitor O_2 saturation to assess ongoing need for oxygen - Use cautiously in severe COPD - Low flow O_2 by nasal prongs may be useful
Malignant Obstruction	■ Steroids - Dexamethasone 8-32 mg/day ÷ BID to TID
Pleural effusion	■ Thoracentesis ■ If recurrent effusions - Talc or doxycyline pleurodesis - Insert Tenchkoff tm catheter for repeat drainage

MAINTAINING COMFORT

PROBLEM	INTERVENTION
Pulmonary edema	■ Furosemide 20-120 mg po prn ■ Appropriate cardiac medications ■ Salt and fluid restriction
Sensation of breathlessness/smothering/ respiratory distress	■ If opioid naïve - Morphine 2.5-5mg po q2-4h prn or 1-2.5 mg sc q1-4h prn ■ If taking opioids - Increase dose of same opioid by 25-50% q4h ■ If severe distress - Administer opioids via sc route - Consider continuous subcutaneous infusion of opioid ■ Manage anxiety - Initiate chlorpromazine at 10-25 mg po q8-12h - Benzodiazepines may be useful in acute distress - Lorazepam 0.25-0.5 mg po or sl or sc q1h prn ■ Changes in respiration (i.e., Cheyne-Stokes breathing) during last hours of life can be distressful to family members - Provide support & reassurance - Continue pharmacologic management for breathlessness
Secretions	■ Use cool mist vaporizer to increase humidity in room (clean daily) ■ Consult physiotherapy to help clear secretions ■ Nebulized saline to loosen thick secretions ■ To reduce secretions - Glycopyrrolate 0.1-0.4 mg sc tid-qid prn - Hyoscine hydrobromide 0.2-0.6 mg sc q4-6h prn - more sedating than glycopyrrolate - 1.5 mg transdermal scopolamine patch behind alternating ears q72h (8-12 hr for onset of action - provide good mouth care and keep mucous membranes moist - ensure adequate hydration ■ avoid oropharyngeal/nasopharyngeal suctioning unless absolutely necessary ■ Noisy secretions during the last hours of life can be very distressing to family as they are often perceived as discomfort - Provide support & reassurance - Continue pharmacologic management for secretions

Complementary Therapies

- Acupuncture
- Aromatherapy

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DYSPHAGIA AND ORAL COMPLICATIONS

Definitions

Dysphagia

- difficulty swallowing

Oral Complications

- refers to oral/esophageal infections, oral ulcers and dry mouth

Presentation[1,2,10]

Symptoms associated with swallowing difficulty include coughing after taking fluids or food, which may indicate aspiration, a "wet voice" during or after eating, and choking episodes. There may be complaints of sore mouth, painful swallowing and chest pain or "heartburn" especially after taking fluids or food. Decreased intake of fluids and/or food may result in weight loss.

Causes[1,2,10]

Associated specific diseases include cerebrovascular accidents, CNS malignancy, dementia, Parkinson's disease, neuromuscular disorders (myasthenia gravis), multiple sclerosis, amyotrophic lateral sclerosis (progressive muscular atrophy). Painful swallowing can occur secondary to acid reflux, oral/esophageal candiasis, radiation treatment to head and neck and esophageal obstruction. Weakness/sedation and poorly fitting dentures also contribute. Medications can affect swallowing as follows:

- Oral phase of swallowing
    - Dry mouth
        - Anticholinergics
        - Agents with anticholinergic activity (e.g. tricyclic antidepressants, phenothiazines, opioids, some anti-emetics)
    - Oral lesions
        - Antineoplastics (e.g. 5-fluorouracil)

        - Corticosteroids
    - Parkinsonian symptoms
        - Neuroleptics
        - Metoclopromide
    - Sedation
        - Benzodiazepines
        - Tricyclic antidepressants
        - Phenothiazines
- Pharyngeal phase of swallowing
    - Parkinsonian symptoms
        - Neuroleptics
        - Metoclopramide
- Esophageal phase of swallowing
    - Direct esophageal injury
        - Tetracycline
        - Doxycycline
        - Corticosteroids
        - Potassium salts
    - Decreased pressure in lower esophageal sphincter (causing reflux)
        - Anticholinergics
        - Agents with anticholinergic activity
        - Some calcium channel blockers (e.g. dihydropyridines)
        - Nitrates

Approaches and Interventions[1,3-11]

- Ensure airway protection before providing anything orally (fluids, foods, medications).
- If a medication is suspected as the cause of dysphagia, the need for that agent should be re-evaluated. If implicated, it should be discontinued or a change made to another agent if possible. A lower dosage should be considered if the specific agent cannot be discontinued
- A speech pathologist, if available, should be consulted for a swallowing assessment.

PROBLEM	INTERVENTION
Acid reflux (can cause painful swallowing)	To neutralize excess acid: ■ Aluminum &/or magnesium containing antacids - 15-30 mls po q2h prn ■ Alginic acid - 10-20 mls or 2-4 chewable tablets po qid pc & hs To reduce acid production: H_2-antagonists ■ ranitidine 150 mg po qhs to bid ■ famotidine 20-40 mg po daily ■ cimetidine 300 mg bid

PROBLEM	INTERVENTION
Acid reflux (can cause painful swallowing)	Proton Pump Inhibitors ■ omeprazole 20-40 mg po daily ■ lansoprazole 15-30 mg po daily ■ pantoprazole 40 mg daily - enteric-coated, do not crush Increase pressure in lower esophageal sphincter thereby decreasing acid reflux: Prokinetic Agents ■ domperidone 10 -20 mg po qid 1/2 hr ac & hs ■ metoclopramide 5-10 mg po qid 1/2 hr ac & hs or 5 mg sc qid 1/2 hr ac & hs - may cause EPS with long-term use
Esophageal ulcers	Protective coating over open ulcers[3] ■ sucralfate 1 gm qid qid ac & hs
Oral candidiasis	Treat infection ■ nystatin 500,000 units qid po swish & swallow x 14 days - can be frozen into popsicle for more palatable administration ■ ketoconazole 200 mg po daily to bid x 14 days ■ itraconazole 100 mg po daily x 14 days - ketoconazole and itraconazole require acidic environment for adequate absorption - concurrent use with H_2-antagonist/proton pump inhibitor can result in treatment failure - if achlorhydria suspected, administer with cola beverage to provide sufficient acid for absorption[4,5] ■ fluconazole 100 mg daily x 14 days - decrease dose if estimated creatinine clearance <50 ml/min ■ Persons with chronic oral candidiasis require longer treatment period (e.g., 6 to 12 months) ■ Azole antifungals (ketoconazole, itraconazole, fluconazole) can inhibit the metabolism of several agents – refer to appropriate drug interaction references - Avoid ketoconazole & itraconazole in persons taking cisapride
Esophageal candidiasis	■ Ketoconazole 400 mg po daily x 4-6 weeks ■ Itraconazole 100 mg po daily x 4-6 weeks ■ Fluconazole 100-200 mg po daily x 4-6 weeks
Mouth care/hygiene	■ Brush teeth and gums regularly with soft brush and fluoride toothpaste or gel - If person is in last hours of life, apply baking soda mouthwash and medications with sponge swabs ■ If gingivitis, brush with chlorhexidene 0.2% oral rinse qid x 30 days - Soak dentures in water with 1 squirt chlorhexadine soap qhs x 30 days

PROBLEM	INTERVENTION

Difficulty taking oral fluids and food	■ Consult speech pathologist if there is difficulty swallowing
	- Identify appropriate feeding techniques
	    - Positioning, compensatory techniques, appropriate utensils
	- Identify most appropriate consistency
	    - Liquids (thin, thick, gelled), solids (minced, pureed)
	    - Consider palatability as well as ease of chewing, swallowing
	- Education & training for senior, family and caregivers regarding nature of swallowing difficulty and strategies to reduce risk
	■ Medications to treat underlying disorders if appropriate (see dysphagia/oral complications, nausea/vomiting)

Dry mouth	■ See dehydration

Aphthous ulcers	■ Saline mouth rinse swish and spit qid
	■ Avoid acidic foods/fluids
	■ Use protective dental pastes
	- Steroid containing
	    - Dab on oral lesions tid to produce a thin film
	    - May decrease pain and shorten duration of episode[6]
	- Non-steroid containing
	    - Dab on oral lesion tid pc & hs to produce a thin film
	- Lidocaine viscous 2%
	    - Dab liquid on oral lesion tid pc & hs
	    - For extensive oral lesions 15 ml swish & spit or swish & swallow qid prn
	    - No food or fluids within 60 minutes of ingestion as may interfere with pharyngeal phase of swallowing

Excessive salivation	■ Scopolamine 1.5 mg transdermal patch behind alternating ears q3days (8-12 hours for effect to begin) ■ Nortriptyline or desipramine 10-25 mg po daily ■ Glycopyrrolate initiate at 1 mg tid - Can cause vision problems and urinary retention in some individuals

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NAUSEA/VOMITING

Presentation[1,2]

Nausea can occur without vomiting and can be more distressing to individuals than vomiting. Suspect decreased gut motility or mechanical obstruction if vomiting occurs without associated nausea, especially after eating.

Malignant obstruction occurs most commonly in persons with abdominal or pelvic disease (i.e., bowel or ovarian cancers). Clinical evaluation should exclude non-malignant causes such as adhesions or pseudo-obstruction secondary to fecal impaction. Features of complete obstruction include large-volume vomitus, nausea worse prior to vomiting and relieved after emesis, no stool in the rectum or stoma, and colicky type abdominal pain. Bowel sounds can be hyperactive (tinkling) but may be absent.

Causes[1-9]

- Nausea/vomiting is associated with several different causes
  - Four general categories as outlined below:

CAUSE	PROBLEM
Visceral Disturbance	
■ Decreased GI motility, slow gastric emptying, gastric stasis, ileus	■ Decreased peristalsis - Post-surgery - Related to anaesthetic - Medications - Anticholinergic agents - Opioids
■ Mechanical obstruction	■ Malignancy - Upper GI tract - Malignancies causing gastric outlet obstruction (e.g., "squashed stomach syndrome") - Lower GI tract - Malignancies (e.g., colon cancer) - Faecal impaction
■ Mucosal irritation (esophageal or gastric)	■ Infections - Esophageal candidiasis

CAUSE	PROBLEM
■ Mucosal irritation (esophageal or gastric)	■ Medications - ASA, NSAIDs most common, see dysphagia for others ■ Acid reflux ■ GI bleed
Chemical Disorders	
■ Medications	■ Affecting the chemoreceptor trigger zone - Opioids - Chemotherapy
■ Biochemical disorders	■ Hypercalcemia - Occurs commonly in malignant myeloma, breast and lung cancers ■ Electrolyte disturbances ■ Uremia ■ Liver failure
Vestibular Disturbances	
■ Medications	■ Affecting the inner ear - Opioids
■ Local tumors or metastases	■ Affects the inner ear or the vestibulocochlear nerve
■ Motion sickness	■ Bone metastases at the base of the skull
CNS Disturbances	
■ Elevated intracranial pressure	■ Results from primary or secondary cerebral tumors
■ Psychological and emotional factors	■ Anxiety ■ Fear of dying ■ Uncontrolled pain

Medications Used to Treat Nausea and Vomiting[1-9]

AGENT	SITE OF ACTION
Antihistamines	
Meclizine	Vestibular centre Vomiting centre
Cyclizine	Vestibular centre Vomiting centre
Dimenhydrinate	Vestibular centre Vomiting centre
Butyrophenones	
Haloperidol	Chemoreceptor trigger zone
Phenothiazines	
Prochlorperazine	Chemoreceptor trigger zone
Methotrimeprazine	Vomiting centre Chemoreceptor trigger zone
Anticholinergic agents	
Hyoscine butylbromide	reduces gut motility - bowel paralysis reduces gastric secretions
Scopolamine	vomiting centre reduces gut motility
Prokinetic agents	
Domperidone	chemoreceptor trigger zone also enhances gut motility
Metoclopramide	chemoreceptor trigger zone also enhances gut motility

AGENT	SITE OF ACTION
Other agents	
■ Octreotide	■ reduces gastric secretions

Approaches and Interventions[1-9]

Non-pharmacologic approaches to nausea and vomiting include reducing and eliminating specific triggers such as odours, foods, among other things. It also helps to keep the room cool. The person should be reassured that he/she does not have to eat if he/she does not feel well. Dry toast, crackers and flat ginger ale sometimes help.

After the person has vomited, it is important to provide good mouth care to clear the taste of emesis. Maintain adequate hydration. As nausea and vomiting are often related to several factors, it is sometimes necessary to use more than one anti-emetic that act by different mechanisms to adequately control symptoms. Select agents with different mechanisms that are compatible in effects.

PROBLEM	INTERVENTION
Visceral disturbances	
■ Decreased GI motility, gastric stasis	■ Prokinetic agents to stimulate peristalsis - Domperidone 10 mg po tid-qid 1/2 hr ac & hs - Metoclopramide 5-10 mg po tid-qid 1/2 hr ac & hs or 5 mg sc tid-qid 1/2 hr ac & hs - All prokinetic agents should be avoided if complete obstruction
■ Mechanical obstruction	■ Restrict oral intake of food/fluids ■ Treat reversible causes of obstruction (i.e., faecal impaction) ■ Treat acid reflux (see dysphagia) ■ Use anti-emetics that act on chemoreceptor trigger zone - Haloperidol 0.5-1.5 mg po or sc tid regularly or prn - sc dose usually 1/2 oral dose - Methotrimeprazine via continuous subcutaneous infusion beginning at 0.25-0.5 mg/hr (6-12 mg/24 hr) or 3-6 mg sc once daily to bid - can be very sedating, inform senior and family ■ Reduce secretions - Hyoscine butylbromide 10-20 mg pr or sc up to 4 times per day (cut suppository in half for 10 mg dose) - can also be given as continuous subcutaneous infusion beginning at 1.25-2.5 mg/hr (30-60 mg/24 hr)

PROBLEM	INTERVENTION
■ Mechanical obstruction	- also reduces gastric motility - useful if complete, irreversible bowel obstruction associated with colic - Octreotide 150 ug sc bid or continuous sc infusion 12.5-25 ug per hour (300-600 ug per 24 hours)
■ Mucosal irritation	■ Avoid acidic foods/fluids ■ Remain in sitting position 30 minutes after eating, drinking fluids or taking medication ■ Treat esophageal infections (see dysphagia) ■ Treat acid reflux (see dysphagia) ■ If NSAID-related - Re-evaluate need for NSAID - Add H_2 antagonist or proton pump inhibitor - If related to other medication, re-evaluate need for medication - Discontinue, change to another agent or lower dose if possible ■ If symptoms remain add anti-emetic acting on chemoreceptor trigger zone as above
Chemical Disorders	
■ Medication-related	■ Use anti-emetic agents that act on chemoreceptor trigger zone
■ Hypercalcemia	■ Hydrate with NS (see dehydration) ■ Consider use of IV bisphosphonate - Pamidronate - Clodronate ■ Use anti-emetic agents that act on chemoreceptor trigger zone
■ Electrolyte abnormalities	■ Correct electrolyte abnormalities and dehydration ■ Use anti-emetic agents that act on chemotrigger receptor zone
Vestibular Disturbances	■ Medicate 60 minutes prior to activity ■ Use medications that act primarily on vestibular nuclei - Dimenhydrinate 12.5-25 mg po or pr q4-6h - Scopolamine 1.5 mg transdermal patch behind alternating ears q72h (8-12 hours for initial effect) - Cyclizine 25-50 mg po or sc tid - Meclizine 25-50 mg po daily to qid -usual maximum dose 100 mg per day

PROBLEM	INTERVENTION
CNS Disturbances	
Elevated intra-cranial pressure	Dexamethasone 4-6 mg po or sc tid Use anti-emetics that act on vomiting centre - Cyclizine 25-50 mg sc tid Anti-emetics that act on chemoreceptor trigger zone - Haloperidol 0.5 – 1.5 mg q6-8 h po or sc - sc dose is usually 1/2 oral dose - Phenothiazines may lower seizure threshold
Anxiety Fearfulness	Offer psychosocial support * Offer spiritual support† Benzodiazepines (see anxiety)

Complementary Therapies

- Therapeutic touch
- Relaxation therapy
- Acupuncture
- Acupressure
  - Sea bands

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DEHYDRATION

Presentation[1-4]

May present as any of the following: decreased or no urine output, confusion, dizziness, weakness or fatigue, poor skin turgor and complaints of thirst or dry mouth. It is important to keep in mind that dehydration may occur even in the presence of ascites, peripheral or pulmonary edema.

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* Additional information on this topic is in Chapter 2.
† Additional information on this topic is in Chapter 7.

Causes[1-4]

Common causes of dehydration include reduced fluid intake, vomiting, use of diuretics and diarrhea.

Approaches and Interventions[1-4]

The issue of dehydration and the need for rehydration requires thoughtful discussion with the person and their family as the issue of food and fluid has important personal and cultural meaning to some individuals*. Hydration may also improve symptoms associated with hypercalcemia and opioid-related delirium in some individuals.[1,2]

PROBLEM	INTERVENTION
Dehydration	■ Offer salt-containing oral fluids if tolerated - Club soda - Tomato based juices - Commercial salt and fluid replacement fluids - Avoid alcohol & caffeine-containing beverages (e.g., coffee, tea, colas) - Act as diuretic ■ Fluids with minimal salt content - Water - Flat ginger ale - Juices (not tomato based) ■ If subcutaneous hydration (hypodermoclysis) recommended and agreed to by the senior and his/her family - Normal saline - Begin infusion at 75-100 ml/hr & titrate rate according to local tolerance at site and fluid requirements - Do not add medications - Exception is potassium chloride up to 20 mmol/L - Preferred placement sites: - Scapular or pectoral areas - Anterior or lateral aspect of thigh - Lateral abdominal wall - Avoid suprapubic area or 2-inch area around umbilicus - Rotate infusion site every 72-96 hours
Dry Mucous Membranes	■ Eyes - Keep conjunctiva moist with: - Ocular lubricant q4h - Artificial tears 2 drops to each eye q1h prn especially if eyes are open - Lips and nares - Reduce evaporation by applying thin layer of petroleum jelly - Avoid petroleum jelly with plastic tubing (i.e., nasal prongs) as it breaks down the plastic

* Additional information on this topic is in Chapters 4 and 8.

PROBLEM	INTERVENTION
Dry Mucous Membranes	■ Mouth - Chew sugarless gum - Suck on hard sugarless lozenges or sour candies - Suck on ice chips - Frequent sips of water - Cool mist vaporizer to increase environmental humidity - Clean vaporizer daily - Avoid acidic foods/fluids (e.g., citrus juices) - Regular mouth care to keep mucous membranes and teeth moist and clean - Use baking soda mouthwash - 1 tsp baking soda, 1 tsp salt, 1 quart tepid water - Avoid alcohol containing mouthwashes - Drying effect - May be irritating - Commercial artificial saliva substitutes (sprays, swabs or gel) applied to lips and inner mouth q1h prn - Avoid lemon-glycerin swabs for mouth care - Glycerin is drying - Lemon is irritating

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SKIN BREAKDOWN/CHRONIC WOUNDS

Definitions[1-3]

Pressure Sore

- Ulcer caused by prolonged pressure on an area of the skin

Fungating Lesion

- Tumour that can be observed at the skin surface
- May break through the skin and cause ulceration

Presentation[1,4]

PROBLEM	INTERVENTION
Stage 1	■ Nonblanchable erythema of intact skin - Do not confuse with reactive hyperemia ■ May be difficult to identify in individuals whose skin is darkly pigmented or discoloured - In these individuals, warmth, edema, induration or hardness may be used as indicators
Stage 2	■ Partial-thickness skin loss involving epidermis and/or dermis ■ Ulcer will be superficial and presents as an abrasion, blister or shallow crater
Stage 3	■ Full-thickness skin loss involving damage or necrosis of subcutaneous tissue ■ May extend down to but not through underlying fascia ■ Ulcer presents as a deep crater with or without undermining of adjacent tissue
Stage 4	■ Full-thickness skin loss with extensive destruction, tissue necrosis or damage to muscle, bone or supporting structures ■ May be associated with undermining of surrounding tissue and sinus tracts

The staging system presented above does not represent a continuum of progressive damage. For example, stage 1 wounds do not have to progress through each stage to become a stage 4 wound and a stage 2 wound is not necessarily more severe than a stage 1 wound.

Causes[1]

The development of pressure sores is related to many factors that include external pressure through direct pressure, friction or shear. Mattress quality and positioning is important as is moisture that occurs with incontinence or diaphoresis. Poor nutritional status is also associated with pressure sores and chronic wounds, especially if the person is dehydrated and/or has a low protein intake. Immobility increases risk and is associated with advanced Parkinson's or Alzheimer disease, severe arthritis and cerebrovascular disease. Finally, age and acute illness are also important considerations.

Approaches and Interventions

It is important to keep in mind that wound procedures and repositioning can cause significant pain. Pain assessment should be conducted prior to and during wound procedures such as dressing changes and debridement. Chronic pain secondary to wounds should also be evaluated. When a person experiences pain secondary to wound procedures or from pressure sores, they should be provided with appropriate analgesia, according to the WHO stepladder.

Appropriate goals for wound healing should be determined since complete wound healing may not be realistic. If this is the case, it is important to set other appropriate goals such as providing adequate pain control for wound-related discomfort, and preventing systemic complications (such as septicemia).

MAINTAINING COMFORT

In order to prevent chronic wounds such as pressure sores, it is important to identify "at risk" individuals by performing a systematic risk assessment using validated assessment tools such as the Norton[5] or Braden[6] Scales. Risk should be reassessed at regular intervals.

While reducing pressure is important, this risk must be balanced with patient comfort during repositioning. Provide analgesics if the person experiences pain during this process.

If the individual is bedbound, repositioning every 2-3 hours is suggested. Pillows or foam wedges can be used to keep bony prominences from direct contact. Devices can also be used to relieve pressure on heels. While in the side-lying position, avoid positioning directly on the trochanter. It can be helpful to reduce amount of time the head of the bed is elevated, as much as the individual's medical condition will allow, to reduce shearing forces. Use lifting devices rather than dragging individuals during transfers and position changes to reduce friction. Pressure-reducing mattresses can be helpful. All donut-type devices should be avoided.

If the individual is chair bound, repositioning every 1-2 hours is suggested. The person should be encouraged to shift their weight every 15 minutes between repositioning. Use pressure-reducing devices for seating surfaces and avoid donut-type devices. The appropriate professional (occupational therapist, physiotherapist) should be consulted regarding posture alignment, weight distribution, balance and stability and pressure relief when positioning individuals.

For persons remaining in bed or those who are able to sit in a chair, a written plan should be available that all caregivers can refer to.

Skin care is another area of importance. The skin should be inspected at least once a day while providing care and a bathing schedule should be developed. When bathing, use tepid, not hot water and a mild, non-abrasive skin cleanser or soap. While many people find massage helpful for muscle pain, do not massage over bony prominences. Environmental factors that contribute to skin breakdown should be minimized such as low humidity and exposure to cold air. Moisturizers can be used for dry skin and skin should be cleaned at the time of soiling if the person is incontinent. If incontinence is present, use a moisture barrier following cleansing and use under-pads or briefs that are adsorbent and present a quick-drying surface to the skin.[7]

PROBLEM	INTERVENTION
Pressure sore	■ Wound assessment on regular basis[8] - Consider use of the PUSH tool[9] - Size & shape - Wound edges - Surrounding skin - Ulcer bed - Tissue colour - Exudate ■ Appropriate wound treatment - Cleansing and irrigation[10] - Use normal saline or special wound cleansers

PROBLEM	INTERVENTION

Pressure sore	- Avoid topical agents that may impair wound healing[11]
	  - If wound healing is not a realistic goal, these agents may be considered to control bacterial load
	- Debridement when appropriate
	  - Mechanical, autolytic or chemical
	  - Aggressive debridement is not appropriate if complete healing of the wound is not a realistic goal
	- Apply appropriate wound dressing (see table below)
	  - Provide adequate pain control if dressing changes cause discomfort

Fungating wounds[3]	■ Develop in the following cancers:
	- Breast
	- Head and neck
	- Skin
	- Vulva
	■ Control tumour growth if possible
	- Chemotherapy
	- Radiation
	- Surgery
	■ Control odour
	- Use odour-absorbent dressings
	- Use air-freshening unit and pleasant aromas
	- Place kitty litter or activated charcoal under individual's bed
	- Consider use of aromatherapy
	- If anaerobic infection causing odour
	  - Topical metronidazole
	    - Can use metronidazole IV solution mixed with 50 ml normal saline and spray onto lesions
	    - Prevents buildup that can occur with metronidazole gel or cream
	  - If topical metronidazole fails, consider oral metronidazole
	■ Control bleeding
	- Topical thromboplastin 1,000-5,000 units sprayed on area
	- Use padding and hemastatic dressings
	- Consider use of silver sulphadiazine or sucralfate paste
	- If risk of tumor invading vessel prepare caregivers
	- Have written plan in place should major bleeding occur
	  - Escort family from room
	  - Provide analgesic and sedative medication
	    - Administer the prescribed breakthrough analgesic via sc route, repeat q5minutes if necessary

PROBLEM	INTERVENTION
Fungating wounds	- If opioid naïve, administer morphine 5 mg sc and repeat q5minutes if necessary - Midazolam 5 mg sc, may repeat q5minutes if necessary - Use dark coloured blankets or towels to cover individual - Caregivers and family will require support following event

Wound dressings

PRODUCT CATEGORY	APPROPRIATE INDICATION
Semi-permeable adhesive films (Transparent films)	■ Primary dressing: - Shallow wound with no exudate - Protectant ■ Secondary dressing: - Cover other dressings
Hydrocolloids	■ Wounds with mild to moderate exudate - Not appropriate if heavy exudate ■ Contraindicated if wound infected with anaerobic organisms ■ Promotes autolytic debridement
Absorptive dressings Alginates	■ Wounds with mild to heavy exudate ■ Bleeding wounds
Foams	■ Wounds with moderate to heavy exudate ■ Allergies to some foam products reported[12]
Hydrofibres	■ Wounds with moderate to heavy exudate
Odour-absorbent	■ Malodorous wounds ■ Fungating wounds ■ Odorous, exudating bleeding wounds

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DELIRIUM

Definitions[1]

Delirium is a disturbance of consciousness with reduced ability to focus, sustain or shift attention. It is accompanied by a change in cognition and/or the development of a perceptual disturbance that is not better accounted for by dementia. It develops over a short period of time (i.e., acute or subacute onset) and tends to fluctuate during the course of the day.

Presentation[1]

This may include disorientation, agitation/restlessness with a decreased and/or fluctuating level of consciousness. There may be rambling or incoherent speech with an inability to name objects or write. Perceptual disturbance such as hallucinations, illusions and misinterpretations of external stimuli may occur. There may be a reversal of the sleep-wake cycle.

Causes[1]

- Frequently multi-factorial
- Medications
  - Anticholinergic agents
  - Agents with anticholinergic activity
    - Be aware of total anticholinergic load
  - Antiparkinsonian agents
  - Benzodiazepines
  - Corticosteroids
  - Digoxin
    - Toxicity may present as delirium
    - Measure digoxin level
  - Lithium
    - Related to toxicity
    - Measure lithium level
  - Opioids
- Infections
- Metabolic disturbances
  - Hypercalcemia
  - Uremia

- Depression
  - May present as agitation, confusion, delusional thinking, hallucinations
- Elevated intra-cranial pressure
  - Primary or secondary CNS tumors
- Subdural hematoma
- Environmental changes
  - Relocation from home to hospital
  - Room changes
- Constipation/fecal impaction
- Urinary retention

Approaches and Interventions[2-5]

- Identify and manage underlying cause or contributing factors whenever possible
- Discontinue medications suspected of causing or contributing to problem
  - If opioid suspected then consider switch to another opioid or decrease dose if possible
- Provide safe, familiar and comfortable environment
  - Minimize risk of falls
- Reassure and reorient the individual frequently
- Have a family member or caregiver sit quietly with the individual if possible

AGENT[6-12]	SITE OF ACTION
Agitation/restlessness	■ Neuroleptics - Haloperidol 0.5 – 1.5 mg po or sc q4-8h -sc dose is usually 1/2 oral dose - Loxapine 2.5-5 mg po or sc q6-12h - sc dose is usually 1/2 oral dose - Risperidone 0.5-1 mg po bid - Olanzapine 2.5-15 mg po daily - Choice of agent depends on side-effect profile and experience - Initiate therapy at lowest possible dose and increase as necessary - Dose around the clock until under control then decrease dose by 25% ■ Benzodiazepines - Add if severe agitation and poor response to optimal doses of neuroleptics - Lorazepam 0.5-2 mg po or sl or sc q6h prn

AGENT	SITE OF ACTION
Hallucinations/perceptual disturbances	■ Reassure individual ■ Neuroleptics - Choice of agent depends on side-effect profile and experience - Initiate therapy at lower end of dosing range and increase over several days to response - Haloperidol 0.5-2 mg po or sc q4-8h -sc dose is usually 1/2 oral dose - Loxapine 2.5-5 mg po or sc q6-12h - sc dose is usually 1/2 oral dose - Risperidone 0.5-1 mg po bid - Olanazepine 2.5-15 mg po once daily
Hallucinations secondary to anti-parkinsonian agents	■ Frequently occurs in advanced stages of Parkinson's disease ■ Discontinue medications in following sequence - Anticholinergics - Amantadine - Selegeline - Dopamine agonists - Decrease dose of levodopa preparations - can result in re-emergence of Parkinsonian symptoms ■ If inadequate response or re-emergence of severe Parkinsonian symptoms consider - Clozapine - Initiate at 12.5 mg qhs and gradually increase to 25-75 mg/day - Can cause agranulocytosis - Biweekly CBC with differential - Can cause orthostatic hypotension - Olanzapine - Initiate at 2.5 mg qhs and gradually increase dose to response (maximum of 15 mg per day) - Some D_2-receptor blocking properties - Potential to worsen Parkinsonian symptoms - Somnolence can be dose limiting

Side-effect profile of neuroleptic agents

AGENT	SEDATION	EPS*	ANTICHOLINERGIC	ORTHOSTATIS
Typical				
Chlorpromazine	++++	+++	+++	++++
Haloperidol	+	+++++	+	+
Loxapine	+++	++++	++	+++
Thioridazine	++++	++	++++	++++
Atypical				
Olanzapine	++	++	+++	++
Quetiapine	+++	++	-	++
Risperidone	+	++	+	++

\+ = very low
++ = low
+++ = moderate
++++ = high
+++++ = very high

Complementary Therapies

- Homeopathy
- Aromatherapy
- Massage therapy
- Music therapy
- Therapeutic touch

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* EPS - extrapyramidal symptoms

DEMENTIA

Definitions[1,2]

Dementia (DSM-IV)

The development of multiple cognitive deficits that include memory impairment and at least one of the following:

- Aphasia
- Apraxia
- Agnosia
- Disturbance in executive functioning

This is also accompanied by a significant decline in social or occupational functioning.

Behavioural symptoms include the following:

- Agitation/restlessness
- Delusions/paranoia
- Physical aggression
- Verbalizations
- Wandering

Presentation[2]

Presentation may be different depending upon type of dementia and stage of the disease:

- Alzheimer Disease
  - Gradual onset
  - Continuing decline of memory
  - At least one additional cognitive domain involved
  - Not explained by other disorders
- Vascular Dementia
  - Associated with cerebrovascular disease
  - Abrupt onset
  - Stepwise decline following another ischemic event
  - Impaired executive functioning
  - Gait disorder
  - Emotional liability
- Frontotemporal Dementia
  - Insidious onset
  - Slow progression of behavioural changes
  - Language changes, including reduction in verbal output
- Lewy Body Dementia
  - Progressive cognitive decline
  - Fluctuating symptoms
  - Recurrent visual hallucinations
  - Extrapyramidal symptoms
  - Hypersensitivity to neuroleptics
  - Repeated falls

Approaches and Interventions[2-10]

PROBLEM	INTERVENTION
Behavioural symptoms	■ Identify and manage any potential causing or contributing factors - Environmental change - Medical illness - Medications - Pain ■ Perform thorough behavioural assessment - Specific behaviour - Onset - Frequency - Duration - Consequences - Precipitating factors - Physical treatments - Assistance with ADLs - Visitors/lack of visitors ■ Initiate non-pharmacologic interventions first - Caregiver approach to individual - Environmental modifications - Recreational activities ■ Pharmacologic therapy if no improvement - Neuroleptics have modest effect on behavioural symptoms - Individuals with Lewy Body dementia will be very sensitive to effects of neuroleptics - Use only if absolutely necessary - Choice of agent depends upon side-effect profile and experience - Haloperidol 0.5-2 mg po or sc q4-8h -sc dose is usually 1/2 oral dose - Loxapine 2.5-5 mg po or sc q6-12h -sc dose is usually 1/2 oral dose - Risperidone 0.5-1 mg po bid - Olanzapine 2.5-15 mg po daily - Quetiapine 25-50 mg po bid - Initiate therapy at lowest possible dose and increase after 2-4 weeks - Document changes in behaviour with each dosing change - If improvement documented, gradually decrease dose monitoring carefully for re-emergence of symptoms - Avoid agents with high anticholinergic effect - Consider trazodone 25-75 mg po qhs if sleep disturbances

Complementary Therapies[11]

- Vitamins
    - Thiamine (B_1)
    - Cobalamin (B_{12})
    - Ascorbic Acid
    - Beta-carotene
    - Vitamin E
- Acetyl-L-carnitine
- Choline
- Lecithin
- Dimethylaminoethanol
- Phosphatidylserine
- Coenzyme Q_{10}
- Herbal agents
    - Ginkgo biloba
        - may increase risk of bleeding
        - do not use with oral anticoagulants, ASA or other NSAIDs
    - Ginseng
- Melatonin

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PAIN

Definition

- An unpleasant sensory or emotional experience[2] that is derived from sensory stimuli and modified by individual memory, expectations and emotions[3]

Presentation[1-3]

Seniors may be reluctant to report pain. Untreated pain can result in depression, decreased socialization/withdrawal, impaired ambulation/decreased mobility, impaired functional ability and sleep disturbances.

Seniors may describe pain using terms other than pain including aching, burning, discomfort, heaviness, "pins and needles", sharp, stabbing, stinging, tingling, and tightness.

Seniors who are cognitively impaired or who have communication difficulties may present with agitated behaviour/restlessness, changes in facial expression (look for furrowing of the brow/tension across forehead), changes in functional ability, changes in gait/decreased mobility, or verbalizations such as crying, groaning and moaning.

Causes [3,4]

- Nociceptive pain results from stimulation of chemical, pressure, stretch and temperature receptors (nociceptors) found throughout the body
  - Somatic
    - Usually well-localized
    - Can be constant or intermittent
    - Often described as gnawing or aching
  - Visceral
    - Usually poorly localized
    - Usually constant
    - Often described as aching, squeezing, penetrating
- Neuropathic pain results from damage or irritation to a specific nerve or group of nerves
  - Dysesthetic
    - Often described as constant burning, "pins & needles"
  - Neuralgic
    - Often described as sharp, stabbing, shooting pain with an electrical feel

Common causes of nociceptive pain in seniors are: arthopathies, malignancy (e.g., bone metastases, tumor infiltration of soft tissue, liver metastases), myalgias, skin and mucosal ulcerations, nonarticular inflammatory disorders and cardiovascular disease.

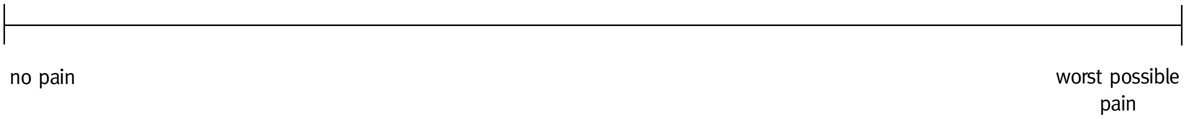
Neuropathic pain is associated with the following conditions: postherpetic pain, diabetic neuropathy, post-stroke pain, post-amputation pain, post-radiation pain, post-surgical pain, trigeminal neuralgia and malignancy (e.g., tumor infiltrated a nerve, tumor is causing nerve compression).

Pain Assessment (refer to Symptom Assessment)

- Goal of pain assessment is to characterize pain by location, intensity , etiology and other factors influencing the pain experience (including psychosocial, spiritual and cultural factors)
- Pain is a subjective symptom and the most accurate evidence of pain is based on the individual's description and self-report
- Comprehensive pain assessment should include the following:
  - Medical history
  - Physical examination
  - Review of relevant laboratory and other diagnostic tests
  - Medication history including over-the-counter medications, homeopathic and/or naturopathic agents

- Identify PQRST characteristics
    - P – provocation and precipitating factors, palliation and relieving factors
    - Q – quality (e.g., burning, gnawing, aching, shooting)
    - R – radiation (e.g., does the pain move)
    - S – severity (use appropriate pain scales – see below)
    - T – timing
- Evaluation of other factors affecting the pain experience (i.e., psychological, social, spiritual, cultural)*
- Evaluation of functional ability
    - Edmonton Functional Assessment Tool[†] (This can be downloaded from The Edmonton Palliative Care Program web site – www.palliative.org)
- Quantitative assessment of severity using a standard pain scale
    - Visual analogue scale (0-10 cm)
    - Numerical scale (0-10)
    - Descriptive scale

1. Visual Analogue Scale



2. Numerical scale

3. Descriptive Scale

Pain Assessment in the Senior with Cognitive Impairment or Communication Difficulties

- Pain can be accurately assessed in those with cognitive impairment or communication difficulties
- Consult speech pathologist regarding communication aids to assist in the assessment
- Identify nonverbal pain behaviour
    - Changes in gait
    - Change in behaviour
        - Agitation
        - Restlessness
        - withdrawn
    - Facial expressions
        - Look for furrowing of the brow, tension across forehead
        - Compare to the Faces Pain Scale[7] for assessment

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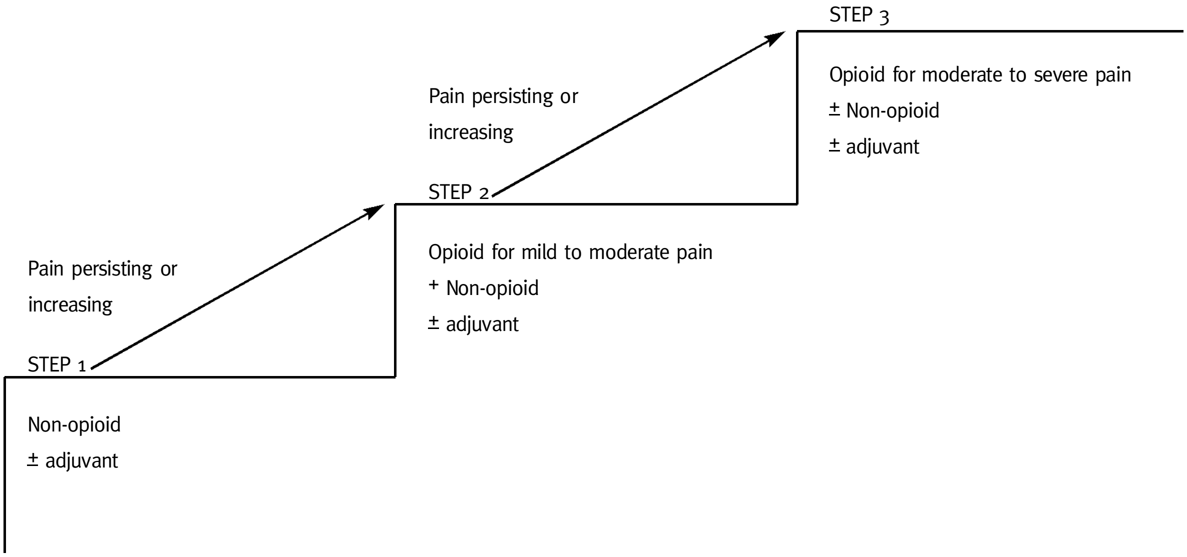
* Additional information on this topic is found in Chapters 2, 6 and 8. See also the Edmonton Palliative Care Program Assessment Tools at www.palliative.org

- Verbalizations
    - Crying
    - Groaning
    - Moaning
        - During the last hours of life, moaning and groaning may be the result of partial closure of the vocal cords due to stress during the dying process and do not necessarily represent pain
        - Interpret verbalizations during this time in the context of other signs and symptoms
        - Pain, even in an unconscious person, is usually associated with furrowing of the brows and/or signs of tension across the forehead

Approaches and Interventions[4-11]

- Provide stepwise analgesia as outlined by the World Heath Organization
    - Not necessary to initiate therapy at Step 1 if person is experiencing moderate to severe pain
    - If a person is experiencing severe pain, initiate therapy at Step 3



- Consider use of other treatment modalities when appropriate
    - Palliative radiotherapy
    - Palliative chemotherapy
- Consider non-pharmacologic modalities
    - Physiotherapy
    - Music therapy
    - Art therapy
    - Relaxation therapy
    - Therapeutic touch

- Address all aspects of suffering*
  - Physical
  - Psychosocial
  - Cultural
  - Spiritual
- Monitor effectiveness of treatment plan on a regular basis
- For medications, consider the following
  - The oral route is the preferred route of administration unless individuals are experiencing severe nausea/vomiting or are unable to swallow
    - Avoid intra-muscular injections as they can be painful
    - Use subcutaneous route for parenteral administration
  - Use "round-the-clock" dosing for individuals who describe or indicate constant pain
  - Use prn dosing for individuals who describe or indicate intermittent pain or for breakthrough pain for persons receiving "round-the-clock" medication
  - Titrate the dose of medication individually
    - Be cautious if person seems to require rapid titration of opioids
    - May be expressing total suffering as pain
    - Determine if other factors are influencing the pain experience
  - Use adjunctive medications when appropriate
  - Avoid the following medications
    - Mixed agonists-antagonists (i.e., pentazocine, butorphanol, nalbuphine)
      - Ceiling effect (no increase in analgesia beyond a specific dose)
      - Adverse CNS effects
      - Can produce withdrawal symptoms in persons taking opioids
    - Partial agonists
      - Ceiling effect
      - Can produce withdrawal symptoms in persons taking opioids
    - Meperidine
      - Active metabolite, normeperidine, can cause confusion, agitation and seizure activity
      - Short duration of action
- Provide ongoing education regarding analgesic medications to persons with pain, their families and caregivers
  - Misconceptions about addiction and tolerance can lead to poor adherence and inadequate pain relief.

PROBLEM[12-19]	INTERVENTION
Arthritic pain	■ Consult physiotherapy - Provide a specific exercise plan to strengthen muscles and minimize gait disorders - Assess mobility and evaluate need for mobility aids - Evaluate TENS - Assess for appropriateness of thermal therapy ■ Medications

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* Additional information on this topic is in Chapters 2, 6 and 8.

PROBLEM	INTERVENTION
Arthritic pain	Step one ■ Acetaminophen 325-650 mg po q4-6h - Maximum dose 4000 mg per 24 hours ■ NSAIDs - Considered second or third line agents due to potential adverse effects - Some clinicians would recommend the addition of codeine before considering NSAIDs - May be more effective than acetaminophen if inflammation present - Add cytoprotective agent if high risk for NSAID-related GI ulceration - Misoprostol 200 ug po tid-qid - Proton pump inhibitor ■ COX-2 specific NSAIDs - May be lower risk of NSAID-related GI ulceration although long-term data in frail seniors is not available Step two ■ Add codeine to above - Codeine 15-30 mg po q4h regularly or prn - Laxatives to prevent opioid-related constipation Step three ■ If inadequate response, discontinue codeine and add strong opioid - Morphine 2.5-5 mg po q4h - Hydromorphone 1 mg po q4h - Oxycodone 2.5-5 mg po q4h ■ Long-acting opioids may be used to simplify the dosing regimen when satisfactory pain control is achieved
Neuropathic pain	■ Consult physiotherapy - Evaluation of TENS - Determine appropriate exercise program to minimize myofascial complications associated with neuropathic pain ■ Based on degree of severity, optimize other analgesics during titration period and decrease dose of these agents as pain control allows ■ Dysesthetic type pain - Tricyclic antidepressants - Desipramine or nortriptyline have lower anticholinergic effects than amitriptyline - Initiate at 10-25 mg po qhs and titrate dose every 5-7 days by 10-25 mg as tolerated - 75-100 mg usual maximum daily dose for pain

PROBLEM	INTERVENTION
Neuropathic pain	- Gabapentin - 100 mg po tid - titrate by 100 mg tid every 3-5 days as tolerated - 600 mg tid usual maximum daily dose for seniors - capsaicin 0.025-0.075% cream applied to affected areas tid-qid - burning associated with application when initiated is transient and decreases within 14 days - wash hands immediately following application - avoid contact with eyes - not recommended if delirium or severe cognitive impairment ■ Neuralgic type pain - Carbamazepine - 100 mg po daily - titrate by 100 mg every 5-7 days as tolerated - 300-400 mg bid usual daily dose in seniors but monitor serum concentration for toxicity - valproic acid - 125 mg po q8h - titrate by 125 mg q8h every 5-7 days - 250-375 mg q8h usual maximum daily dose in seniors - phenytoin - 100 mg q8h - monitor plasma levels - do not exceed 80 umol/l ■ Consider referral for nerve block ■ Consider radiotherapy if related to malignancy (i.e., nerve compression) ■ Consider referral to palliative care specialist if pain persists
Bone pain	■ Provide stepwise analgesia according to severity rating - NSAIDs can be helpful but side-effects may limit their use - The role of COX-2 specific agents has not been defined for bone pain related to malignancy ■ Consider addition of dexamethasone 2-4 mg po if bone metastases ■ Depending on prognosis - Consider adding a biphosphonate if breast cancer or malignant myeloma with bone metastases ■ Consider referral for radiotherapy if localized bone pain secondary to bone metastases ■ Refer to palliative care specialist if pain persists ■ Calcitonin 100-200 IU sc or intranasally if pain related to vertebral fracture - Can administer test dose 25 IU sc to determine if allergy

EQUIANALGESIC DOSES OF OPIOIDS*

Medication	PO dose	PO:SC ratio
Morphine	10 mg	2 mg PO = 1 mg SC
Codeine	100 mg	2 mg PO = 1 mg SC
Oxycodone	5 mg	-
Hydromorphone	2 mg	2 mg PO = 1 mg SC

Note: when converting from one opioid to another (i.e. morphine to hydromorphone) decrease the dose of new opioid by 20-30% to account for incomplete cross-tolerance between agents

AVAILABLE DOSAGE FORMS[+]

MEDICATION	DOSAGE FORMS
Codeine	
■ Oral-immediate release	■ Suspension 5 mg/ml Tablets 15 mg, 30 mg
■ Oral-slow release	■ 100 mg, 150 mg, 200 mg (usually administer q12h)
■ Parenteral (for sc injection)	■ 30 mg/ml, 60 mg/ml
Oxycodone	
■ Oral – immediate release	■ Oxycodone alone – 5 mg, 10 mg With acetaminophen – 2.5 mg + 325 mg acetaminophen – 5 mg + 325 mg acetaminophen
■ Oral- slow release	■ Tablets -10 mg, 20 mg, 40 mg, 80 mg (usually administer q12h)
■ Rectal– immediate release	■ Suppository - 10 mg, 20 mg
Morphine	
■ Oral – immediate release	■ Syrup – 1 mg/ml, 5 mg/ml, 10 mg/ml, 20 mg/ml ■ Drops – 20 mg/ml, 50 mg/ml

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* Table adapted from reference 4.

[+] Table adapted from reference 5.

MEDICATION	DOSAGE FORMS
Oral – immediate release	Tablets- 5 mg, 10 mg, 20 mg, 25 mg, 30 mg, 50 mg
Oral – slow release	Tablets/capsules - 10 mg, 15 mg, 30 mg, 60 mg, 100 mg, 200 mg (usually administer q12h)
Oral-once daily slow release	Capsules – 20 mg, 50 mg, 100 mg (usually administer once daily)
Rectal – slow release	Suppositories – 30 mg, 60 mg, 100 mg, 200 mg (usually administer q12h)
Parenteral (for sc injection)	0.5 mg/ml, 1 mg/ml, 2 mg/ml, 10 mg/ml, 15 mg/ml, 25 mg/ml, 50 mg/ml
Hydromorphone	
Oral – immediate release	Syrup – 1 mg/ml Tablets – 1 mg, 2 mg, 4 mg, 8 mg
Oral – slow release	Capsules – 3 mg, 6 mg, 12 mg, 24 mg (usually administer q12h)
Rectal – immediate release	Suppository – 3 mg
Parenteral (for sc injection)	2 mg/ml, 10 mg/ml, 20 mg/ml, 50 mg/ml

Complementary Therapies

- Massage
- Acupuncture

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SUMMARY RECOMMENDATIONS FOR TREATMENT

- Assess symptoms in a systematic and multi-dimensional fashion.
- Recognize that seniors may describe symptoms in a non-specific manner.
- Manage symptoms with appropriate use of medications and non-pharmacologic interventions.
- Be conscious of the potential side-effects of medications and take preventative steps to avoid them.

chapter 4

ETHICAL ISSUES

INTRODUCTION

Goals of this Chapter are to:
- clarify the major ethical issues that caregivers may encounter when caring for seniors at the end of life
- help caregivers understand the underlying values and morals for the care they are providing
- provide tools for health care and social service providers to help them in their decision-making when taking care of seniors

This chapter explores ethical issues that occur in the care of seniors at the end of life. The chapter is intended to assist caregivers in understanding the value and moral basis of the care they are providing. It also provides caregivers with tools to help them make care-related choices in the face of ethical dilemmas. Each of us makes decisions that relate to our own values which include those we have grown up with coupled with those we acquire as adults. Our values may not be the same as those of our colleagues, patients, or their families. People can agree upon common values, yet disagree about what ought to be done in specific situations. These differences can create problems because of the need to understand, acknowledge and consider our own values while respecting the values of others who are participants in ethically-challenging situations.

The care of seniors at the end of life can be a rewarding, challenging, and deeply troubling task. Health care and social service providers face many challenges when providing end-of-life care to seniors. When providing such care, these providers must typically:
- follow the code of ethics for their profession
- follow policies and practices of their workplace which has mission statements or other information that give some framework for ethical practice
- be accountable to the seniors, the professionals themselves, the profession and the place of work

While there is not always one 'correct' answer to ethical dilemmas, the process of open communication among health care and social service providers, seniors, and family members can assure that ethical decisions that are reasonably acceptable to the parties concerned and the reasons for them can be achieved. A shared understanding of the goals of care and an appreciation of how these goals might be reached for seniors at the end of life is an important part of this process.

WAYS OF THINKING ABOUT ETHICS: COMMON FRAMEWORKS

One influential contemporary framework for considering ethical issues presents four principles to help address ethical challenges and dilemmas for North American hospital ethicists and health care and social service providers.[1] The four principles, applied to seniors, are:

- Respect for autonomy: This principle entails accepting the senior's right to make decisions for the conduct of life and also acting on that respect. It also means treating the senior with respect and dignity.
- Non-maleficence: With a senior who is dying, this principle to not inflict harm intentionally might require that painful medical tests not be carried out, since there may be no chance of benefit for the senior.
- Beneficence: Treatment must have some potential to help the senior, and health care and social service providers are morally obligated to provide such care.
- Justice: Health care professionals must treat seniors equitably and fairly. It is not acceptable to decide who receives a scarce resource on the basis of characteristics such as gender or ethnicity.[2]

Although these principles are useful when making treatment and other decisions, invoking them often does not solve complex ethical dilemmas. Sometimes the principles may conflict, sometimes it is not clear which principle is the most important in a situation. Many questions still remain:

- What ought to be done when seniors request treatment that is regarded by the health care and social service provider as too risky or not useful?
- What ought to be done when the senior and the family differ in their preferences?
- Should health care and social service providers acquiesce to requests when a clearly terminally ill senior wants "everything done"?

There are some concerns when thinking about this principle-based approach:

- The framework is based on a rigidity of rules and principles.
- It may presuppose a "wrong" starting place.
- It does not take enough of the circumstances of everyday life into account.
- It is culturally-based and, therefore, may not apply to everyone.

Some ethicists favour a case-based approach to dealing with ethical dilemmas. This approach holds that moral judgements are based on the understanding of specific situations, rather than from an extraction of moral theory or principles.[3] In this approach, principles must arise from the cases, or situations that occur, and cannot be decided upon ahead of time. Previous similar cases are used as a guide to help solve current dilemmas.

Another approach suggests that ethical analysis must make sense in the real world rather than being based solely on abstract concepts.

- The context of a situation and the relationships of the various parties involved must be adequately considered for a proper decision to be made.
- Individuals are seen as unique, while at the same time belonging to a community of people.
- The oppression of women within society must be considered seriously and equal rights and opportunities for women must be available within society.[4]
- The fact that the majority of seniors are women suggests this group may be disadvantaged when resource allocation and rationing decisions are made.

The moral component of the care of seniors at the end of life is always present, but often hidden. By thinking about the issues and how they might be resolved, health care and social service providers can integrate the practice of ethical decision-making into their clinical caregiving activities.

INDIVIDUAL DECISIONS

Every health care and social service provider faces ethical issues when caring for seniors who are at the end of life, and each must decide what activities are morally acceptable. For example, some may have moral objections to removing or withholding treatment in certain circumstances; some may have difficulty caring for a senior who has decided to stop eating. Certain exercises can help in decision-making. It is useful to think about one's own values at a time when there is not an urgent decision to be made, so that at the time of a decision one can state an objection (or support) of a decision, and be able to justify it to others. When this kind of moral soul searching does not take place, health care and social service providers may find themselves in situations which cause them "moral distress". If repeated over and over, this may lead to frustration, job dissatisfaction, and burnout.

ETHICAL ISSUES

INFORMATION DISCLOSURE - TELLING THE TRUTH

It is a difficult decision to know what to tell a senior who has a terminal illness - how do you communicate "bad news"? Until recently, health care and social service providers often felt that their duty of non-maleficence meant that they should not give a patient very bad news. However, this viewpoint has changed.

Knowledge allows seniors to participate in autonomous choices about care-related options. This knowledge may also help seniors to think about how to spend the latter part of life. Seniors have a right to:

- accurate information concerning diagnosis, prognosis, treatment
- treatment alternatives, risks and benefits, and help to understand the implications of that information
- information provided in a timely, compassionate manner
- information even if they have not directly asked for it (Not disclosing certain information may be considered ethically as no different from deliberately lying.)

There are some potential qualifications to the statements noted above:

- If the senior indicates that he/she does not want to know, this should be respected. However, it is not enough to assume the senior does not want to know.[5]
- There is a limited exception to telling the truth through the concept of "therapeutic privilege".

This means that it may be preferable to withhold information when the health care and social service provider reasonably believes that disclosing it would cause substantial harm to the senior.[6] There must be evidence that the senior would be harmed (e.g., a recent attempt at suicide); however, it is not enough to assume the senior might be harmed.

Family Requests for the Nondisclosure of Information

Sometimes a family member requests that the senior not be told certain information, often because of an honest belief that the loved one will be harmed by the knowledge. It is necessary to explore the basis for the request:

- Does the family know how the senior dealt with bad news in the past?
- Is the family having difficulty facing the prospect of their loved one's death?
- Are they afraid that the senior will become worse or 'give up' if the truth is revealed?

Understanding the motivations can help the health care and social service provider work with the family and the senior. However, the family's request does not change the health care and social service provider's obligation to be truthful with the senior unless, for example, the patient has clearly indicated that he/she wants information to be communicated only to the family - as an autonomous choice. This information is further discussed in Chapter 8 in the cultural context of end-of-life care.

PROMOTING INFORMED CONSENT

Informed consent requires that the senior has sufficient information to understand what is involved in the decision, understands that information, and makes a decision freely, based on personal values and wishes.[7] The obligation to obtain informed consent for health care is important and is a legal requirement for many types of health care interactions in Canada.

Elements of Informed Consent

In order for consent to be truly informed, a number of elements must be present:[8]

- The senior must be capable of making the decision.
- Information about the decision must be disclosed to the senior. Opinions have differed about exactly what information should be given to the individual. In Ontario, for example, The Health Care Consent Act (1996) stipulates that the information must include:
    - the nature of the treatment
    - the expected benefits
    - the material risks and side effects associated with it
    - alternative courses of action
    - the likely consequences of not having treatment

It is also important that the senior understand the information. In order for this to happen, the health care and social service provider may have to use a variety of techniques to be sure the information is clear, such as clarifying specific points and asking questions to assess understanding.

The best approach to informing a senior will be based on the health care and social service provider's knowledge of the senior's needs and abilities.

- The senior must communicate consent, though this need not be in writing.

Process of Informed Consent

Supporting patient-centred decision-making means providing an environment for the senior to be able to make a choice. Techniques for supporting a senior in decision-making include:

- providing time for discussion
- encouraging questions
- suggesting other resources for information and for emotional support
- respecting the senior as having the right to make personal health care decisions

The process of informed consent must provide the senior with the tools and support required to make an informed decision. For the health care and social service provider, this means being open to the possibility of the senior's refusal of treatment or the choice of a treatment which would not be the provider's preference.

SUBSTITUTE DECISION-MAKING

There are times when a senior will not be capable of making a decision about health care. At this point, it will be necessary to call upon a substitute or proxy to make such decisions. A substitute decision-maker:

- needs the same elements of informed consent as the senior
- has the same right to information and understanding as the senior
- may be chosen through varying provincial frameworks that may have different legal implications

There are some guidelines for substitute decision-makers to use when making health care decisions:[9]

- Carry out the senior's wishes if these are known. The individual may have expressed the wishes in a variety of ways, which could include discussions with the substitute or a written advance directive.
- When the senior has not clearly expressed preferred wishes that are applicable to the clinical situation, the substitute can rely on the values held by the individual, and on opinions on the topic that he/she may have previously expressed.
- In the absence of knowing what the senior would want in the situation, the substitute should act in his/her 'best interest' by:
    - taking all of the factors about the senior's condition and treatment alternatives into account along with the known or assumed values and attitudes of the patient
    - accepting that they are not being asked to make decisions based on their personal values but, rather, what appears to be the preference or appropriate choice for the senior

The health care and social service provider can help the substitute decision-maker by providing information and being supportive of the substitute decision-maker in carrying out this responsibility.

CAPACITY AND CAPACITY ASSESSMENT

The cornerstone of respect for autonomy is translated into honouring the senior's right to make personal health care decisions, and supporting the decision whether or not we agree with those decisions. The determination as to when to remove decision-making authority is an ethical as well as legal task. Health care and social service providers are often faced with such decisions when they are caring for seniors at the end of their lives.

In order to be capable of making health care decisions, a person must be able to "understand information relevant to a treatment decision and appreciate the reasonably foreseeable consequences of a decision or lack of decision".[10]

Global versus Specific Accounts of Capacity

The traditional understanding of incapacity, of 'global incapacity', was that once a person was declared incompetent, decision-making authority was removed forever, or until such time as the condition causing it was reversed.

- This meant that all decisions of any import were made by the senior's surrogate on behalf of the individual.
- The rationale was to protect the senior from making bad or dangerous decisions.
- There is now a recognition that many frail, ill and dependent seniors may, in fact, need to be protected from having others assume their decision-making authority when it is not required for their well-being.

Today there is a new understanding of what it means to be incapable (incompetent). This is the concept of "specific" incapacity which means that decision-making authority is removed from a person only for those situations in which the capacity is compromised.

- A senior may not be able to make a decision concerning a treatment that requires a complex risk-benefit explanation, but may be capable of making a decision about a simpler type of treatment, especially one which has occurred previously.
- A senior may not be able to make a decision about a specific treatment, but may be capable of designating the surrogate who should make the decision.

Presumption of Capacity

Given this contemporary understanding of capacity, the first principle of determining a senior's ability to make decisions is the presumption of capacity.

- It is not enough to base the assumption of incapacity on a diagnostic classification of Alzheimer Disease.
- The senior must be able to communicate in some fashion his/her preferences that would be expected to be reasonably stable over time.[11]

Assessments of Capacity

The assessment of capacity must relate to the specific decision that needs to be made. While standard tests of cognitive ability are useful in a comprehensive assessment of the senior, they may not be sufficient to determine whether the older person is capable of making a given decision. The assessment should determine whether the senior:

- understands the nature of the decision to be made and the information relevant to it
- appreciates the consequences of the choices he/she makes[12]

It is the responsibility of the assessor with the help of those caring for the senior to be sure that the assessment is as fair as possible.[13] In order to provide conditions that will give the senior the best chance of succeeding, one should:

- provide a test that is meaningful to the decision, individualized and realistic[14]
- choose a time(s), location, and an assessor the senior is comfortable with
- use communication techniques that enhance the ability of the senior to understand the assessment

Fluctuations in Capacity

A senior's capacity to make decisions may fluctuate over time or as the medical condition changes.

- A senior whose competency fluctuates is not necessarily unable to make decisions.
- If, during lucid moments, the senior is able to communicate stable preferences, this may be taken as a valid expression of a capable preference or decision.[15]

Capacity and Advance Care Planning

Although a senior must be capable when an advance directive or power of attorney is executed, this does not mean that the senior's current wishes or attitudes do not need to be considered.

- For example, a surrogate decision-maker attempting to decide about whether artificial feeding is what the senior would have wanted or is in that senior's best interest needs to consider the reaction of the person to the treatment. Does there appear to be resistance to the treatment or does it appear to be causing unacceptable levels of discomfort?

For the health care and social service provider, it is useful to note that advance directives do not replace the need for the role of a substitute decision-maker.

- An advance directive is primarily meant to inform the substitute as to the wishes of the senior.
- An advance directive or durable power of attorney for personal care does not come into effect until the senior is incapable of making the type of decisions covered in the document.

ADVANCE CARE PLANNING

In the last decade, there has been growing support for planning in advance for decisions that may have to be made at the end of life. People may choose to do this planning formally by means of advance directives, or informally, through discussions with family members, friends, and health care and social service providers or a combination of both methods.

Advance Directives

Advance directives are documents in which an individual sets out wishes regarding health care decisions that may have to be made at a time when the individual is not capable of making them. For a senior, this incapacity is usually due to cognitive impairment or the terminal stages of illness. Advance directives usually (but need not) contain two sections:

- an instructional section where the senior indicates what type of treatment he/she would like to have or refuses, depending on various health situations
- a proxy directive, naming the person or persons who are to make the decisions on behalf of the senior, and perhaps naming those who should not make decisions for them

Advance directives are now recognized as legal, or at least deserving of consideration, in nearly all provinces. Seniors, who may be reluctant to use advance directives, may prefer that their families make decisions for them and they are likely to discuss their treatment preferences with them.[16] It may be that the most important aspect of advance planning for end-of-life situations is the conversations about these issues between individuals and their families including those who will be expected to make surrogate decisions. However, putting all decisions into writing is always best.

Many health care facilities have had difficulty with advance directives in that some seniors refuse to complete them. Some facilities use a "level of intervention"[17] document to deal with advance care planning.

Discussions with Family Members/Substitute Decision-Makers

Discussions with family members are an important part of the advance care planning process. An important reason for the whole process is to relieve loved ones from the burden of making decisions, or of watching the senior go through 'an unnecessarily long process of dying'.[18] Recent Canadian research suggests that the systematic implementation of a program to increase use of advance directives reduces health care service utilization without affecting satisfaction or mortality.[19]

Conversations with Health Care and Social Service Providers

Very few people discuss advance care planning with any health care and social service provider.[20] However, these providers can be a source of a great deal of information and support when seniors are making decisions about the types of treatment they prefer at the end of life. Health care and social service providers can promote these discussions by:

- approaching the topic sensitively
- providing uninterrupted time
- educating about options available
- being available to listen to concerns

Starting discussions about end-of-life care early will allow the senior time to gather needed information, in order to consider wishes or preferences that need to be communicated to others.

CONFIDENTIALITY: PROTECTING HEALTH RECORDS OF SENIORS

In the process of receiving health care, seniors are asked to reveal information about themselves that they might not share with anyone else. Confidentiality:

- is expected by health care and social service providers who have a duty to treat this information with respect and is stipulated by virtually all health care and social service providers' Codes of Ethics
- means sharing the senior's information only with those who are involved in the care of the individual and who have a need to know

Keeping information confidential is a way of respecting a senior's autonomy; the individual retains control over what happens to the information. It also promotes mutual trust and communication between health care and social service providers and seniors.

An ethical dilemma occurs when a senior asks one health care and social service provider to promise not to reveal something discussed to other health care and social service providers that may be necessary for proper care. This can often be dealt with by discussing ahead of time the limits of confidentiality.

Methods to protect confidentiality include:

- providing private areas for seniors to have discussions with health care and social service providers
- keeping health records in a secure place (even institution or agency personnel who are not caring for the senior should not have access)
- refraining from discussing patient information in public areas such as elevators and cafeterias
- keeping blackboards or bulletin boards containing patient information out of public view
- consulting with others, including the senior, when there is a question about the appropriateness of sharing information

There are times when it is permissible, even obligatory, to breach confidentiality. These situations usually occur when there is an unacceptable risk of harm to the senior or someone else, and include:

- certain communicable diseases that must be reported by law to the authorities
- a medical condition such as a mental illness that may result in personal harm or harm to others; such information may be revealed to police if necessary for proper care, safety and public protection
- a reasonable suspicion of elder abuse; such cases must be reported in many jurisdictions

Respecting Privacy

It can be difficult to keep information from the senior's family, but unless the senior gives permission either formally or informally, it is not acceptable to discuss the individual's condition with family members. It cannot be assumed that because someone is older, family members are the primary avenue of communication about the senior's condition. The relationship and the lines of communication should be established early in the relationship between the health care and social service provider and the senior.

Access to Records

The Supreme Court of Canada has enshrined the right of patients to have access to their health records. The information is the patient's even if the actual document belongs to the agency, institution or individual provider. This confirms the concept that the provision of information is part of the trusting relationship between health care and social service provider and patient.

WITHHOLDING AND WITHDRAWING TREATMENTS

Caring for seniors who are at the end of life may involve making decisions about withholding or withdrawing life sustaining treatments.

- The right of patients to refuse such treatment has been acknowledged ethically through the principle of respect for autonomy, and legally through court decisions such as Malette v. Shulman, and Nancy B. v. Hotel-Dieu de Quebec.

While such decisions are made together with the patient or surrogate, health care and social service providers may be left with questions about their own role in the patient's death. For some practitioners, the decision to discontinue a treatment may seem like killing the patient; for others, the more distressing scenario is to not start a treatment that may help sustain someone who would otherwise certainly die. These are circumstances where health care and social service providers have to explore their own values to decide what their own ethical response will be and how they will react to requests for such interventions.

CPR AND DNR ORDERS

Changing Attitudes toward Cardiopulmonary Resuscitation

While cardiopulmonary resuscitation (CPR) was once considered to be part of standard care for anyone who had a cardiac or pulmonary arrest, recent studies have shown that there are many situations where its use is of questionable benefit:[21]

- many seniors who are terminally ill
- some people with multiple medical problems

For other seniors, even though they may potentially benefit from CPR, they may choose not to have it. In these cases, it may be appropriate to include do not attempt resuscitation (DNR) status as part of the plan of care. The Joint Statement on Resuscitative Interventions (1995) provides guidelines for policy makers and health care and social service providers about which patients might and might not be suitable for CPR and how suitable decisions can be made.

With respect to seniors, the discussion and decision about CPR status should not be made in isolation. It should evolve from the goals of care for the senior. These goals, decided upon by the health care and social service providers, the senior and/or family, can help to determine what treatments are appropriate for this situation. There needs to be clear communication with seniors, surrogate decision-makers and family members about what other care will be provided even when the decision has been made to withhold some treatments.

Professional Judgement and Patient Choice

A difficult CPR decision can occur when the senior or family disagree with the judgement of the physician as to the appropriateness of attempting CPR. There may be disagreement about what constitutes beneficial treatment. It is only by listening and discussing goals that an understanding may be reached.

Disputes about Attempting CPR

It is possible that a health care and social service provider may disagree with another health care professional about CPR in a particular situation. This may be because of different values, different judgements about the benefits of the procedure, or different information about or understanding of the senior's wishes. There are some consequences:

- The senior may receive an unwanted intervention or not receive a wanted intervention.
- When the nurses or junior physicians believe that CPR is wrong (for whatever reason), but there is no order from

the senior's physician for DNR, the results might be what is known colloquially as a 'slow code'. This occurs when a patient has a cardiac or respiratory arrest and there is a deliberate delay in starting CPR and calling the team to help. The delay makes it less likely that resuscitation will be successful. It also makes it more likely that if cardiac and respiratory function are restored, the patient will be left in a worse state than before. Slow codes are not an ethical way to resolve a dilemma about CPR status.

ETHICAL ISSUES IN NUTRITION AND HYDRATION

Some of the most perplexing ethical dilemmas in the care of seniors occur around issues of nutrition and hydration. The situations encountered may be of several types.

Refusal of Food and Fluid by Seniors

There are some seniors who make the decision to stop eating and drinking.

- In a palliative situation, this may be as a result of the illness that reduces appetite and makes the process of eating difficult or unpleasant.
- A person who is in stable physical health may also make the decision.
- It may be the result of a remedial condition such as clinical depression.

If the senior is now at the end of life because of a personal decision not to eat or drink, attempts should be made to learn why he/she has made this decision. It may be the result of a remedial condition such as clinical depression that can be treated. Respecting the senior's autonomy by honouring this decision can be difficult for providers.

Feeding

When a senior, because of physical or cognitive illness, is no longer able to self-feed, it becomes the task of family members or health care and social service providers to undertake the feeding process. When the senior resists being fed by another, it is reasonable for the health care and social service providers and senior or proxy to discuss the issue of whether and how best to provide nourishment.

Tube Feeding

Many health care facilities provide brochures describing the advantages and disadvantages of artificial nutrition. This information, along with discussions with health care and social service providers, can help seniors and family members faced with this issue.

Artificial Hydration with Seniors

The provision of artificial hydration (usually intravenous or sub-cutaneous fluids) to a dying senior was long considered a comfort measure, used to prevent the person from dying an uncomfortable death due to dehydration rather than the underlying disease. It has been recently suggested that, in most instances, the burden of artificial hydration may outweigh the benefits for the person who is at the very end of life.[22] This makes the decision about artificial hydration a complex one in which the senior's wishes and values, along with the current goals of treatment must be considered. The health care and social service providers responsible for the senior's care should provide education for both the person and family about the reasons for the recommendation and assurances that the senior is not being abandoned.

ETHICAL ISSUES IN PAIN CONTROL*

Palliative Care

Although a clearly stated goal in palliative care is the relief of pain, even this objective is not without its moral dimension. Health care and social service providers may disagree about the amount of analgesic medication that should be given, leaving them feeling that they are not able to meet the palliative goal, or in contrast, that they are hastening the senior's death.

- It is important to realize that it is ethically acceptable or even obligatory to provide, at the senior's request, pain relief that may also, as a consequence of the medication's other effects, shorten the patient's life.
- It is also important to realize that some seniors could choose to have a certain level of pain in order to avoid sedation.

Substitute Decision-Makers

When a substitute decision-maker is making decisions about pain relief, there may be conflicts between that person and the health care team about appropriate scheduling or amounts of medication. A process to follow in this situation would include:

- exploring the reasoning for the substitute decision-maker's decisions, and explaining the health care and social service provider's concerns
- following up on the substitute decision-maker's reasoning or concerns. Is the substitute having difficulty dealing with the impending death of the senior? What would the senior want?
- determining whether the health care and social service provider believes that the substitute decision-maker is neither acting on the request of the senior nor in the senior's best interests. If so, outside help (e.g., legal intervention) may be considered.

Medical Futility and End-of-Life Care for Seniors

When discussions about withholding or withdrawing treatment take place, they often turn on the concept of futility. It seems useful to be able to say that a particular treatment is "futile", and therefore it will not be attempted, but this term is open to various interpretations.

Medical futility has been defined as "a medical conclusion that a therapy is of no value to a patient and should not be prescribed".[23] Even this definition, however, raises concerns:

- **What is the definition of 'no value'?** Short time survival may not seem to be of value to the health care team, but it may be of considerable value to the senior.
- **Who makes the decision about how low a chance of success (20%, 5%, 1%) there must be for a treatment to be defined as futile?**
- **Is it possible to think of futility in a non-value laden sense?** Many think not - When health care and social service providers are reluctant to agree to treatments that patients want, it is because of a "profound sense that further treatment would be fundamentally wrong".[24]

It is only by open communication between seniors, family members, and health care and social service providers that treatment decisions can be reached. Relying on the view that a treatment is futile may result in avoidance of the frank discussion of the senior's prognosis and alternatives for treatment.

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* Additional information on this topic is in Chapters 7 and 9.

ADDRESSING ETHICAL CONFLICTS IN END-OF-LIFE CARE

There has been some important recent work on addressing ethical conflicts between health care and social service providers and persons receiving care.[25]

PARTICIPANTS IN CONFLICTS

Many of the above issues result in conflict in the provision of care. While it is not necessary for everyone to agree on all points in order to work together, it is important to respect others' points of view and to take them into account when treatment goals and a plan of care is decided upon.

Disputes between Senior/Family and Health Care and Social Service Providers

There may be several reasons for differences between what seniors or family members and health care and social service providers see as appropriate treatment or goals of care. Open communication is key to resolution. While it may be tempting for health care and social service providers to use the authority they possess to convince the seniors or family of the correctness of the provider's point of view, being aware of one's own inherent authority in the situation can be the first step to avoiding its abuse.

Disputes within Health Care Teams

It is in the nature of teamwork that differences of opinion about the "right" course of action will often occur. There can also be significant disputes between administrators and the health care team which requires resolution. In these instances, the issue becomes how these differences are addressed:

- Are minority views listened to and considered?
- What support is there for a team member who cannot in conscience take part in a decision that has been made?
- For the individual, is the decision one that can be accepted even though it does not coincide with personal beliefs? If not, what is the next course of action?

This could include meeting again with the team, consulting an ethicist, ethics committee, or other outside resource, being reassigned or resigning in an extreme case. If the team member believes that a senior is being harmed by the decision, this may mean a whole other set of actions from notifying administrators to taking legal action.

When there are differences within the health care team, the members must decide how this will be presented to the senior and/or family. The differences among team members should be presented in a way that is understandable to the senior. Acknowledging disagreement in the team can often leave the senior or family feeling better able to express their own conflicts and sources of concern.

USING ETHICAL FRAMEWORKS TO RESOLVE DISPUTES

One way to help resolve differences in complex and conflictual situations is to use an ethical framework[26] to provide a reference point on which to measure process and decisions. The purpose of any of these frameworks is to provide a process which assists participants to:

- structure discussion
- consider the relevant ethical principles
- express their own values
- explore alternatives
- make a decision

While frameworks can assist in achieving these objectives, they need to be used in a spirit of a team (including the senior and family) coming together on an equal moral footing to solve a problem or resolve a dilemma. All the participants need to feel that communication has been open and that they have been heard. If this has been the case, even if disagreements persist, at least there will be understanding among the participants of why and how the decisions have been made.

ETHICS COMMITTEES

Most acute care facilities have ethics committees that can provide help in situations where the resolution of a dilemma has not been achieved. Ethics committees, generally made up of people from a number of disciplines, are less common in long-term care facilities, community agencies and hospices. In general, a health care and social service provider, the senior or family may initiate a consultation. While the roles of ethics committees depend on the organization, common ones include:

- assisting in the definition and clarification of the issues
- identifying options
- making recommendations or suggestions as to how a dilemma might be resolved

In most organizations, the recommendations of the ethics committee are not binding; decision-making authority remains with the appropriate person (e.g., the senior, the family or physician, among others).

Sometimes a solution to the dilemma cannot be found among team members, the senior or family members despite the input of an ethics committee.

- Mediation or dispute resolution may be attempted if the resources exist.
- In extreme cases, legal recourse may be necessary, but is usually considered as a last resort.

ASSISTED SUICIDE AND EUTHANASIA

Perhaps no subject in the care of individuals who are terminally ill has been as hotly debated as that of assisted suicide and euthanasia. Awareness of the topic was heightened when the Supreme Court of Canada in 1993 denied the appeal of Sue Rodriguez to have assisted suicide legalized so that she could choose the method and time of her death. Subsequently, the Canadian Senate (1995), after a lengthy period of study and public consultation, produced a report that addressed many of the issues. Although the report recommended some changes to the criminal code, none has been made as yet that substantially affects the prohibition of euthanasia or assisted suicide. Any type of euthanasia is a criminal offense, as is assisting someone to commit suicide. (Actually attempting or committing suicide is not a criminal offense.)

Definitions

- **Assisted Suicide**: the act of intentionally killing oneself with the assistance of another who provides the knowledge, means, or both[27]
- **Euthanasia**: a deliberate act undertaken by one person with the intention of ending the life of another person to relieve that person's suffering where that act is the cause of death[28]

Assisted Suicide

Despite the fact that it is illegal in Canada, health care and social service providers still may be faced with requests for assisted suicide or euthanasia by seniors. The question becomes how best to respond in such situations. Suggestions include:

- listening to the request to understand what is really being asked. For example, a request to 'end it all' or 'get it over with' may be related to present suffering, depression, and fear of what is to come[29]
- reassuring the senior based on his or her expressed concerns
- maintaining a dialogue, so that the senior has someone to talk to
- letting the senior know that this is an illegal act
- calling on a colleague, social worker, chaplain, or other appropriate person to be there for the senior

PRIORITY SETTING AND RESOURCE ALLOCATION

The story is familiar. The population is aging, and with aging comes greater use of the health care system. At the same time, resources within the health care system are progressively strained. The issue is likely to become even more contentious as the proportion of seniors within society increases.

JUSTICE AND MACRO-LEVEL ISSUES

The Canada Health Act (1984) is the broad and general framework within which health care resource allocation takes place in Canada:

- It has many limitations within the structure and scope of the Act that includes limiting coverage based on medical necessity and is primarily limited to hospital and physician services.
- Most provinces have actually expanded the range of coverage under provincial health care systems to cover services beyond those mandated by the Canada Health Act such as medication coverage to various populations, community-based services and non-medical health professional services. As more services are available in the community, health care and social service providers must be aware that there is no entitlement to these services provided by the Act.

Despite the provisions of the Canada Health Act, at the macro level of allocation, decisions are made by governments as to what resources should be designated for health care as a whole, and then how the funding should be apportioned within the health care system. With its principle of universality, The Canada Health Act does not allow discrimination based on age.[30]

Choosing Among Individuals

It is the medical practitioner's decision as to which of a variety of available medical treatments should be offered to a patient for a given condition. Although various criteria are used in different situations, among the considerations that often enter into deliberations in deciding on distribution of resources include:

- the person with the greatest need
- the person with the greatest likelihood of benefit
- the person who may have many dependents
- the person with the likelihood of the longest duration of benefit
- persons whose value to society is extraordinary
- first come, first served

These criteria may all be used at different times. Some are more ethically acceptable than others. While need may be considered the usual reason why a person would receive treatment, some resources (e.g., Intensive Care Unit or palliative care beds) are usually assigned on a first come, first served basis.

There is no clear answer as to which of these criteria might be used at any given time, but they may all be considered in challenging situations. Each agency or institution may decide on criteria for determining need under various circumstances in order to maximize distributing resources in an equitable manner.

Access to Palliative Care for Seniors

In keeping with a generally increased understanding of the benefits of palliative care, long-term care institutions are becoming more aware of the need for palliative care for their senior residents who are in the terminal stage of disease. The recognized benefits include an increase in the quality of the dying process and the assistance and support afforded to family members.[31]

ETHICAL ISSUES IN RESEARCH WITH SENIORS RECEIVING END-OF-LIFE CARE: PROTECTING VULNERABLE HUMAN SUBJECTS

One of the tenets of responsibly conducted research is the protection of those who are, or will become, research subjects. Seniors who are at the end of their lives are a particularly vulnerable group:

- They may be unfamiliar with the concept and processes of research.
- They may be desperate to find something to alleviate symptoms or cure their disease.

Health care and social service providers have a responsibility to be sure that seniors' rights to informed consent, privacy and confidentiality are protected when they participate in research studies, and that their health and well-being are not unnecessarily compromised.

CONCLUSION

Every health care and social service provider caring for seniors at the end of life faces ethical issues daily. The issues often revolve around the tension between respecting the autonomy of seniors and acting beneficently toward them, i.e., in a way that we consider to be in their best interest. We have presented issues that are common, and suggestions for ways of thinking about these issues and resolving dilemmas. By understanding our own values, and those of the people around us, we can recognize and deal with the ethical dimension that is inherent in the practice of health care.

Seniors are important, integral and vital participants of Canadian society. Health care and social service providers need to assure seniors that their enormous value is uppermost when their care is undertaken. The legacy of strength, experience and wisdom that resides in this population is important and the ethical issues that surround the care of seniors must always be taken into consideration, especially when dealing with the difficult issues that surround the end of life.

SUMMARY RECOMMENDATIONS FOR PRACTICE

- Ensure that professional code of ethics and workplace policies are followed.
- Incorporate the principles of autonomy, beneficence and non-maleficence into all treatment and care-related decisions and interventions.
- Base treatment and care-related decisions on the need of the senior and the likelihood of benefits.
- Strive for honest and compassionate communication about diagnoses, prognosis and the risks and benefits of treatment and care, including those related to withholding or withdrawing treatment, nutrition and hydration, and pain control.
- Conduct fair assessments of capacity that give the senior every opportunity to perform at the highest level.
- Respect the privacy of seniors and maintain the confidentiality of their health records.

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chapter 5

DELIVERY OF END-OF-LIFE CARE

INTRODUCTION

Goals of this Chapter are to:

- define hospice palliative care and end-of-life care
- dispel myths and misconceptions surrounding end-of-life care
- help seniors and caregivers understand their care options
- explore the challenges within the provision of care and provide recommendations to meet these challenges

In his keynote address to the First International Conference on Palliative Care of the Elderly in Toronto in 1989, Dr. Balfour Mount noted the following similarities between palliative care and geriatric practice:

> *Both make the whole person and his or her family the focus of care, while seeking to enhance quality of life and maintain the dignity and autonomy of the individual. Judicious use of investigations are advocated and both eschew unwarranted treatment while providing symptom control and relief of suffering. Both are necessarily multi-disciplinary and both are areas which prompt phobic reactions from society at large. Finally, to carry the parallel still further, in medicine, both Geriatrics and Palliative Care are new medical technologies which challenge the restorative, often aggressive and increasingly technological practices in technological areas of medicine.*[1]

This early recognition of the need for strong linkages between geriatric care and palliative care has, until now, not been fully realized. The publication of this GUIDE represents a tangible move to better integrate end-of-life care for seniors and hospice palliative care.

By blending what is traditionally thought of as "end-of-life care" with the principles and practice of hospice palliative care, health care and social service providers can offer seniors and their families a full spectrum of choices and options in terms of care, treatment and support, extending through the period of bereavement. The end result can be better quality of life for patient and caregivers, free of unnecessary pain, suffering and discontinuity of care.

Case Study: Hospice Palliative Care vs. End-of-Life Care

Aimée, a senior suffering from a chronic illness, was offered the choice of being put on a respirator to help her battle an acute upper respiratory infection. She refused, fearing utter dependence on the respirator, and chose instead to take her chances of living a shorter life with dignity. She later moved to a centre offering palliative care where she was able to lead a quality-filled life and die in relative comfort. People like Aimée, who become increasingly frail in their later years and suffer from terminal illness, are most likely to benefit from palliative care.[2] This example shows the strength of palliative care for older people when the end of life is relatively near.

End-of-life care for seniors requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement.
Executive Committee, End-of-Life Care Project, Health Canada, 1998

Hospice palliative care aims to relieve the suffering and improve the quality of life of persons who are living with or dying from illness, or those who are bereaved.
Board of Directors, Canadian Palliative Care Association, 1998

Note: While use of the term "hospice palliative care" encompasses all programs and services that offer services based on the following principles of care, for purposes of brevity in this chapter, the terms "palliative care" and "hospice palliative care" may be used interchangeably.

SOME MYTHS AND MISCONCEPTIONS ABOUT HOSPICE PALLIATIVE CARE*

- The Canadian health system has adequate resources in place to provide high quality end-of-life care/palliative care to the growing numbers of seniors and their family caregivers.
- Health care and social service providers have the necessary education and training to provide good end-of-life/ hospice palliative care to seniors.
- The delivery of palliative care is the same for persons of all ages.
- Dying and death at home are always better than dying and death in an institutional setting such as a hospital, nursing home or residential home.
- Home care services are equally available and accessible in all communities.
- Seniors are always prepared to die when faced with a life-threatening illness.
- All seniors in Canada have equal access to palliative care in their own community.
- Palliative care is only appropriate at the very end of life.
- Palliative care is most appropriate for younger persons.
- Palliative care is only for persons with cancer.
- Pain is an expected part of aging.
- Seniors with dementia and seniors with a life-threatening illness receive comparable end-of-life/hospice palliative care.

PHILOSOPHY AND PRINCIPLES OF HOSPICE PALLIATIVE CARE

Hospice palliative care:

- involves and respects seniors and those who are closest to them
- is competent, compassionate and comprehensive and informed by scientific evidence, values, personal and professional experience

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* Additional information on this topic is in Chapter 1.

- promotes optimal autonomy and independence in decision-making
- is linguistically, culturally, spiritually and geographically relevant
- depends on an informed public and clinicians with strong interpersonal skills, clinical knowledge, technical proficiency and respect for individuals

The following principles of hospice palliative care are adapted from "Palliative Care: Towards a Consensus in Standardized Principles of Practice"[3] and are intended to guide the development of interdisciplinary program standards in all settings that provide care at the end of life. Use of these standards is voluntary. The range and type of services offered by individual programs may differ significantly. This can be confusing for seniors and their caregivers. Knowledge of these principles as well as the different ways in which palliative care can be offered will allow seniors to be better informed when making health-related decisions. As well, a list of sample questions is included for use by seniors and their families.

1. Meet Physical, Psychological, Social, Spiritual and Practical Expectations/Needs

Care is directed towards meeting the physical, psychological, social and spiritual and practical expectations/needs of the senior and family with sensitivity to their personal, cultural and religious values, beliefs and practices. The approach to care is holistic in that it addresses overall quality of life.

2. Access

Seniors and families have timely access to information and the services provided by palliative care when they need and are prepared to accept them. Information and services are provided in a language they can understand. Essential palliative care services are available 24 hours per day, seven days per week.

3. Equal Availability without Discrimination

Palliative Care Services are equally available to all regardless of their age, gender, national and ethnic origin, geographical location, race, colour, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, family status.

4. Ethics

The ethical principles of autonomy, beneficence, non-maleficence, justice, truth-telling and confidentiality are integrated into the provision of care and program development.

5. Right to Information

It is the senior's right to be informed about his/her disease, potential treatments and outcomes, appropriate resources and options.

It is the family caregiver and health care and social service provider's right to be informed about the disease, potential treatments and outcomes, appropriate resources and options, respecting the senior's right to confidentiality.

6. Right to Choice/Empowerment

Decisions are made by the senior and family in collaboration with health care and social service providers, respecting the level of participation desired by the senior and family. The senior and family's choices for care, settings of care and information sharing are respected.

7. Unit of Care

The unit of care is the senior and family (as defined by the senior).

8. Interdisciplinary Team

An interdisciplinary team of health care and social service providers working collaboratively with the senior and family provides care. Physical, mental and emotional changes may have implications for involvement of the senior, and his or her primary caregiver, as part of the interdisciplinary team.

9. Continuity of Care

A coordinated, continuous plan of care that minimizes duplication is maintained across all settings of care, from admission of the senior to bereavement support for the family.

10. Community Collaboration Through Partnerships and Mutual Support

The palliative care needs of a community can only be met through the collaborative efforts of available services in partnership at senior care and programmatic levels.

11. Governance

Governance and administration are essential to support the program and ensure accountability. Broad-based governance includes community representatives, health care and social service providers, seniors and families.

12. Quality of Care

Care is delivered by all health care and social service providers within professionally accepted standards of conduct and practice. Programs will utilize the expertise of qualified providers and trained volunteers. Seniors and families should ask relevant questions of their health care and social service provider, the program or facility administrator to ensure that their needs can be adequately met.

13. Program Evaluation

Program evaluation is essential to the delivery of quality palliative care and to the maintenance of standards of conduct and practice.

14. Education, Information, Research and Advocacy for Palliative Care

Education, information, research and advocacy for the development and maintenance of public policy, palliative care standards and resources are essential to improve the delivery of palliative care.

QUESTIONS TO CONSIDER WHEN MAKING CHOICES RELATED TO END-OF-LIFE CARE

The following questions are intended to assist the decision-making of seniors and their families:

- If you have chosen to remain at home, what support services do you need? Are they available to you? Are there limits to that service? Will there be a cost to you (e.g., for private nursing, medications, supplies, transportation, lost wages)? Can you afford this cost? What will you do if you cannot?

- What are the options for care if your family is in need of respite or is no longer able to cope with your care at home?
- If you are considering placement in a nursing home, what are the minimum standards of care under provincial legislation? Is it licensed and accredited? Can the local placement coordination service tell you about the palliative care programs that are offered by individual nursing homes? Will the nursing home grant you a tour before you make your decision?
- If you are considering placement in a residential or retirement home, are there any government guidelines or standards regulating care? What is the ratio of staff members to residents? What is the level of staff education or training? Is qualified nursing care available? What arrangements exist for medical consultation/ support? Are residents' rooms safe, comfortable and reasonably attractive? What are the standards of cleanliness? Are there opportunities for socialization?
- Is there a specialized palliative care team within the home care program, long-term care facility or hospital?
- What are the criteria for admission to the hospice palliative care service and how can you be referred to that program?
- What specific services are provided by the program?
- Is there 24 hour access, seven days per week to services?
- What is the protocol for managing pain and other symptoms?
- How are advance directives managed?

SETTINGS OF CARE

End-of-life care/palliative care can be provided in various settings which can be categorized as hospital-based care, community-based care and long-term care. While each program may offer a different combination of services, all should adhere to the principles and philosophy of palliative care. Established criteria are used to guide decision-making about admissions to in-patient settings such as palliative care units and residential hospices. Reasons for admission include pain and symptom management. Other palliative care needs include safety issues or inability of family to cope, respite, or terminal care during the final weeks or days of life. The ethical principles of autonomy, beneficence, non-maleficence, justice, truth telling and confidentiality are integrated into the provision of care and program development.

HOSPITAL-BASED CARE

The availability and type of palliative care programs in hospitals varies from institution to institution.[4]

Specialist Consultation Teams

- The palliative care consultation team usually includes a physician(s), nurses or clinical nurse specialist, social worker, pharmacist, spiritual adviser and volunteers.[5]
- At the request of the patient's primary care team, the palliative care consultants visit the patient to perform assessments, give advice about optimum symptom control measures, challenge therapy that seems to be inappropriately aggressive in the face of advanced disease. They may suggest changes in the nursing care plan to improve comfort or provide psychological or spiritual assistance to the patient or staff members. In cases where the patient's needs require special palliative care skills, the consultant may provide direct patient care. Volunteers supplement busy staff members by performing basic hands-on comfort care measures, offering friendly visiting or providing the family with respite.[6]

- Other health care and social service providers may be part of the consultation team, becoming involved with a patient as needed. They advise the primary care team from the perspective of their particular discipline: pharmacy, home care case management, rehabilitation and complementary therapy, psychology, psychiatry, nutrition, home support and others.[7]
- Some hospital-based palliative care consultation teams offer telephone or home visitation support to teams providing primary care to patients living at home or in another facility.
- Not all hospitals have a palliative care consultation team. The patient's primary care team may involve, if available, a palliative care consultation team for advice on any aspect of palliative care from time of diagnosis through the bereavement phase of care.

Scattered Beds

- The palliative care patient is admitted to any unit within the hospital[8] including general surgery, general medicine, oncology and other specialist units.
- The senior's day-to-day care is provided by a primary care team that includes a physician and staff on the unit.

Designated Beds

- The senior is admitted to a unit where there is a grouping of a specific number of beds for palliative care patients. There may be admission criteria for these beds. Non-palliative care patients are usually admitted onto the same unit.
- The patient's day-to-day care is provided by a primary care team that includes a physician and staff members on the unit who are specialized in hospice palliative care.
- A hospital with designated beds may also have a palliative care consultation team; however, this varies from one institution to another. The patient's primary care team may request the involvement of the palliative care consultation team for advice on any aspect of palliative care from the time of diagnosis through the bereavement phase of care.

Palliative Care Unit

- The senior is admitted to a unit within the hospital where there are a specific number of beds for palliative care patients only. Bereavement support is available for family members.
- Not all team members will be involved at the same time or with all patients. Their involvement will depend upon the needs of the senior and family, as well as available resources.

Outpatient Ambulatory Care Clinics

- Outpatient services may be appropriate for palliative care patients who are able to attend appointments. The service allows patients, family members and the family physician to obtain palliative care specialist advice about the management of symptomatic problems.[9]
- A clinic may be affiliated with a cancer centre, a hospital or another palliative care program.

COMMUNITY-BASED CARE

Residential Hospice

- A residential hospice is a home-like facility with a specific number of beds, where around-the-clock care is provided to palliative care patients. It may be affiliated with a hospital or other palliative care program. Hospices affiliated with hospitals are usually separated geographically from the institution.
- The patient's day-to-day care is provided by a palliative care team including a physician(s), nurses, volunteers and other disciplines as available, such as social work, nutrition, rehabilitation therapy, complementary therapy and others.

Day Hospice/Day Respite

- The services provided by day hospice are usually available to both palliative care patients and their family members. Most day hospices provide respite for the senior and for the caregiver who may or may not be employed outside the home. Bereavement support is frequently available.
- A day hospice may be one of the services provided by a palliative care program or it may be a stand-alone program. The terms 'day respite' and 'day away' are used interchangeably with day hospice.
- A day hospice is not usually available five days a week and 24 hour residential care is not offered; therefore it can be considered an adjunct of another palliative care service.[10]
- Whether the format of the day hospice program is based on the medical or social model of care or a combination of both[11], its aim is to maintain or improve a patient's quality of life, provide holistic care and help the individual live at home for as long as he/she wishes.[12] An effort is made to keep the environment as home-like and clinically low key as possible.[13]
- The medical model of day hospice emphasizes patient assessment, professional advice, and liaison with the patient's family physician and other members of the primary care team. Wound care, bathing/ personal care, administration of medications, bowel care and advice may be provided.[14] Access to a palliative care team, a pharmacy or treatments such as chemotherapy or radiotherapy may be related to the attachment of the day hospice to a specific palliative care program.[15]
- The social model of day hospice emphasizes socialization and diversional activities.[16] It involves a variety of disciplines associated with the day hospice including volunteers, spiritual advisors, complementary therapists, rehabilitation therapists, social workers, dieticians and others.[17]
- Day hospice may include one or more complementary therapies such as massage, aromatherapy, reflexology, music therapy, therapeutic touch and reiki. Social outings or off-site programming, such as attending theatre performances, may be part of day hospice.[18]

Home Care

- The patient's day-to-day care in the home setting may be planned and provided by a team of generalist practitioners or palliative care specialists, or a combination of both.
- Palliative care services provided to the senior at home vary from community to community, and from province to province, depending upon available resources. Many Canadians wrongly assume that home care is one of the services guaranteed under the terms of the Canada Health Act, only to discover at a time of need that there can be a significant cost attached and that necessary services may not be readily available.
- A generalist team providing day-to-day patient care usually includes a physician(s), home care nurses, a case manager and personal support workers. Their caseloads consist of a mix of patients who are post-operative, chronically ill and receiving palliative care.[19] Other team members are involved as needed and available.
- A specialist palliative care team usually includes a physician, clinical nurse specialist or nurse, social worker, spiritual advisor and volunteers. Other specialists may include a case manager, physiotherapist, occupational therapist, pharmacist and others as needed and available. The team may be affiliated with a hospital, a home health care agency, or organized as an independent agency.
- The availability and type of specialist palliative care team varies from one community to another. A specialist palliative care team may provide a consultation service, thereby becoming involved in the senior's care at the request of the primary care team. In some communities, a specialist palliative care team provides the senior's day-to-day care.

Palliative Care Volunteer Visiting

- Hospice Palliative care volunteer visiting services are available in many, but not all, communities. Volunteers may provide support to seniors whether they are at home or in a facility. However, this varies from one visiting service to another.
- Hospice Palliative care volunteers, all of whom receive specialized training, offer additional support through friendly visiting, companionship, family respite or sitting with a senior during the final days of life.
- Some volunteer services also provide bereavement support.

Quick Response Teams/Emergency Response Teams

- A quick response team provides an emergency "crisis intervention" service[20] to support seniors and families at home, avoiding visits to the hospital emergency room or hospital admission where possible.
- This service is usually available 24 hours a day, seven days per week.
- Some palliative care programs offer quick response teams as part of their service.

LONG-TERM CARE

Long-Term Care Facilities

- The nursing home is considered to be the resident's home, with other residents and staff members regarded as surrogate family. The resident's day-to-day care is provided by the facility's attending physician or the resident's family physician, nurses, social workers, personal support workers, therapists, dietitians, spiritual advisors. Some facilities also provide volunteers.
- More and more, residents are remaining in the nursing home for end-of-life/palliative care, rather than being transferred to an acute care facility. As a result, the complexity of care provided in the long-term care setting is increasing.[21]
- Some long-term care facilities designate a room or suite for the resident and family to use during the final days or weeks of life, while other facilities have a designated palliative care team or a unit with staff members who specialize in palliative care.
- Palliative care programs external to the facility may be available to residents, families and staff members. Palliative care consultation teams can provide back-up to the facility for advice on pain and symptom management and other palliative care needs.
- Palliative care volunteer visiting services can offer additional support.

Retirement and Residential Facilities

- These private pay facilities are generally for seniors who are active and independent but who require some assisted living services such as meal preparation, laundry and housekeeping services, medication supervision or monitoring of vital signs.
- Facilities vary in location, size, price, amenities, programs and services.[22]
- A visiting physician or physician on call may be available. Around the clock nursing care is NOT provided; therefore, arrangements need to be made in advance to assure palliative patients receive appropriate care as necessary. The local home care program (funded by the province) may provide health care services to persons living in a facility, such as nursing and physiotherapy visits. A palliative care consultation team, external to the retirement or residential facility, may be available to offer advice on pain and symptom management and other palliative care needs. Palliative care volunteer visiting may also be available.
- It may become necessary for a senior who is terminally ill to be transferred to an appropriate care setting if family is unavailable to provide support, or if services provided by the facility and/or home care are inadequate to meet the senior's needs.

SELF-HELP AND SUPPORT GROUPS

- Self-help groups are defined as small, autonomous, open groups that meet regularly in which members share common experiences of suffering and meet each other as equals.[23] Bereavement support is an integral part of palliative care for family members or caregivers. Bereavement support can be located through local palliative care programs, funeral homes, spiritual advisors and community directories. It may be offered through one-to-one telephone contact, visits by trained volunteers or support group meetings. Self-help or support groups may be more useful early in the course of the illness or during the period of bereavement rather than during the period of most intense caregiving at the end of life.
- Participation is voluntary and there is generally no membership fee. Support groups can benefit seniors living with an illness or condition as well as their caregivers or family members.
- Self-help groups are informally structured, open-ended and generally utilize the experience of participants rather than professionals. Some self-help groups, however, do utilize professional expertise (for example, to address complex medical/social issues, to bring together seniors or caregivers with a common interest and to overcome potential barriers to success such as transportation or mobility problems).
- Support groups are intended to complement, not replace, health care and social service providers.
- Self-help groups may function through face-to-face meetings, telephone networks or internet groups, depending on individual need and demographics. For example, seniors who are geographically isolated may benefit from a telephone network or internet group.
- Self-help groups offer mutual aid through the sharing of experiences, information and coping strategies. Participants have the opportunity to contribute as well as to receive.
- Benefits may include practical advice, new perspectives or outlooks, information about new resources, innovative approaches or an enhanced support network.
- Participation may lessen feelings of isolation, marginalization or hopelessness.

CHALLENGES TO THE DELIVERY OF END-OF-LIFE CARE FOR SENIORS

Challenges to the provision of good end-of-life care and good palliative care are numerous for consumers, health care and social service providers, administrators and policy makers. The rapid aging of the Canadian population and the substantial cost of providing end-of-life care both have significant implications for our health system, especially since calculations have not been based on a palliative model of care.[24] Moreover, resource allocation is inadequate to support the choice to die at home.

Many health care and social service providers and non-professional caregivers who work with seniors in various settings do not have access to necessary education and training to provide good end-of-life care.[25] They may not be aware of the various palliative care resources in the community.

Standards of practice of end-of-life/palliative care should recognize the uniqueness of geriatric palliative care for seniors in the same way the palliative care needs of such diverse populations as children, persons with HIV/AIDS and injection drug users have been addressed by the development of specific guidelines and educational tools.

Challenge: To overcome "ageism," which can influence treatment options offered to seniors, based on the assumption of reduced functional expectations.

Recommendations:

- More research on the changes on the various body systems as a result of aging; to improve assessment, care, treatment and support based on the individual condition and needs of each senior and his/her family.
- Education and training programs for health care and social service providers to include information about aging in standard curricula.
- Education about the experience of pain in seniors and how to treat pain, rather than dismissing it as part of the aging process.[26]

Challenge: To improve knowledge about the implications of the presence of one or more chronic illnesses among seniors at the end of life, which may make diagnosis and treatment complex.

Recommendation:

- More research on the implications of multiple illness and/or medical conditions, multiple symptoms and possible interactions of treatments on seniors.

Challenge: To recognize and address the potential for medication overuse and/or misuse.*

Seniors use more prescription and over the counter medications than younger persons and are more likely to be at risk for polypharmacy (the prescribing of multiple and at times unnecessary drugs), drug interactions, adverse drug reactions and non-compliance.[27]

Recommendations: A full review of health status and a baseline medication assessment.

- Carry out a "brown bag" medication review[28] in which the senior is asked to bring all medications (prescriptions, over the counter products and so-called "natural" remedies) to the health care and social service provider.
- Record the medication history over a period of several days to obtain an accurate picture of medication use by seniors, whether at home or on admission to a facility.
- Ascertain possible use of multiple physicians and/or pharmacies, possible drug interactions and/or duplications of medications and non-compliance with prescribing guidelines.
- Simplify the drug regimen by reviewing schedules and eliminating unnecessary medications and duplication.
- Coordinate the medications prescribed by all involved physicians and make a full medication record available to all health care and social service providers.
- Make sure the senior and his/her family caregiver understand the reason for each medication, prescribing guidelines, possible adverse side effects and consequences of non-compliance.
- Provide written instructions, using clear language and large print. Review the instructions with the senior and his/her caregiver to be sure the purpose of the medication, the prescription instructions and possible side effects are understood. Because seniors may relay on recommendations from family members, friends, various pharmacists, health food store staff members and others, inappropriate medications or products may be in use without full understanding of their properties, interactions and health consequences.
- Undertake regular reviews of the senior's medications, evaluating whether or not each medication should be continued, adjusted or discontinued.
- Ascertain reasons for non-compliance. These may include financial concerns, unwillingness or inability to follow prescribing instructions, not understanding the purpose of the medication, mobility limitations which prevent the senior from travelling to fill the prescription and the scheduling of medications that may be complicated, confusing or cause unpleasant side effects. Containers may be difficult, if not impossible, for seniors to open. There may also be hoarding of medications for later use.

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* Additional information on this topic is in Chapter 3.

- Compile lists of possible financial assistance for pharmaceutical needs for needy seniors. At this time, provincial drug plans do not provide uniform coverage which means seniors and their caregivers may, in some situations, feel financial constraints and independently decide not to use or to discontinue medications.
- Carry out appropriate senior, caregiver and health care and social service provider education on aspects of medication use and misuse. The community pharmacist would also make a major contribution to the care plan.
- Develop strategies for monitoring of medications and interventions when appropriate.

Challenge: To help seniors to acknowledge their need for assistance.

Many seniors fear becoming a burden on family members and are reluctant to acknowledge the need for help. Caregivers may be reluctant to acknowledge the need for help due to possible financial concerns or the fear that introducing a new caregiver will adversely affect the senior's well-being.

In addition to better information about diagnosis, prognosis, treatment options, what to expect and what community resources are available to support them, family caregivers need psychosocial support. The concept of "burdening" is often part of the palliative care experience for parents, spouses and adult children who may find themselves in the position of assuming caregiving responsibilities.[29]

Caregiver burnout and stress is a very real problem for many family members caring for a senior who has an advanced life-threatening illness or dementia. A number of studies document caregiver stress[30] noting that caregivers for persons with dementia experience greater stress than caregivers for persons with a life-threatening illness. Clinical depression, anxiety, a sense of isolation, physical illness and infection are symptomatic of caregiver stress.[31] The assumption of caregiving responsibilities can create considerable economic burden through out of pocket expenses and lost wages. While the majority of Canadians state a preference for dying at home, death at home does not necessarily result in "death with peace and dignity."[32]

Recommendations:

- Advocate for a national home and community care program to ensure that end-of-life care services are available and accessible throughout Canada.
- Advocate for provincially-funded home care to increase resource allocations for seniors and their family caregivers, recognizing that the numbers of seniors being cared for at home is increasing, with family members assuming ever-greater caregiving responsibilities.
- Advocate for models of care which promote integration, continuity, common data collection, uniform, validated symptom assessment tools and consistent care management strategies.
- Develop and implement standardized surveillance strategies to more accurately evaluate the real outcomes of community-based care in terms of health, caregiver burden, quality of life and economic consequences to seniors and their families.
- Be cognizant of the nature and extent of home care resources available in the community when planning care at home for seniors.
- Consider introduction of substitute caregivers to assume the caregiving responsibilities normally expected of a family caregiver, in order that seniors living alone are not excluded from home care programs.
- Allocate sufficient resources to address excessively long waiting lists for placement in nursing homes or long-term care facilities.
- Advocate for national/provincial regulations, licensing and uniform standards of care in all settings that purport to offer end-of-life care and/or hospice palliative care to seniors.

Challenge: To remove barriers to access of essential health services in the community.

Access to services can be difficult for seniors because of problems related to access, mobility and transportation issues.[33]

Recommendations:

- Health care and social service providers should utilize a checklist approach to ensure the following:
  - Handicapped parking spaces are near the main entrance.
  - The main door is at ground level and accessible from sidewalks without curbs.
  - The main door can be opened electronically (since many doors are too heavy to be easily opened).
  - Doorways to all offices and examining rooms are wide enough to accommodate wheelchairs and walkers.
  - Reception area is easily accessible.
  - Coat area is away from other doors and out of line of traffic.
  - Examining rooms are equipped with an examining table that is easily accessible and wall-mounted equipment is placed at corresponding heights.
  - Privacy and confidentiality is respected through use of sound-proofing, hearing amplifiers and other means.
  - Staff members are trained to be understanding of the needs of seniors.
  - Health care and social service providers in the community should have directions available, information about public transportation routes and schedules as well as any transportation assistance programs in the community.
  - Health care and social service providers should keep an updated list of other health care resources in the community that might be accessed by seniors.
  - Health care and social service providers should address potential cultural barriers to care through an approach variously described as "cultural assessment" or "cultural "brokerage."[34]

Challenge: To promote seniors' appropriate use of self-help or support groups, recognizing that they may be reluctant to share intimate feelings or acknowledge their need for help.

Seniors may have special needs which must be met in order to participate, e.g., transportation, accessibility of meeting space, accommodation of sensory loss. As well, they may be unaware of the existence of a group which could be of benefit to them.

Recommendations:

- Health care and social service providers should be familiar with current self-help/support services available in the community in order to provide relevant information to seniors and their caregivers.
- Communities need to publicize the existence of self-help groups through a variety of channels such as local religious institutions, seniors' groups, United Way, hospitals, clinics, health care and social service providers, relevant websites, government departments at all levels and local chapters of national disease organizations.

Challenge: To recognize unique needs of seniors related to grief and loss.

Many seniors have experienced numerous significant losses related to independence, financial security, health, death of spouse, other family members and friends. As seniors approach the end of life or the final phase of terminal illness, they or their family may experience both "shadow grief" (cumulative grief for previous losses) and/or anticipatory grief.[35]

Recommendations:

- Health care and social service providers who work with seniors should receive education and training in recognizing signs of grieving or bereavement in order to offer appropriate support or refer to other community resources for grief support
- Health care and social service providers who work with seniors should have access to appropriate bereavement support services to lessen their stress as caregivers.

Challenge: To meet the end-of-life care needs of seniors living in rural communities more effectively.

Seniors in rural communities in all provinces continue to be underserved and underserviced in terms of access to palliative care.[36]

Recommendations:

- Adopt regional approach to delivery of care such as that developed by the Edmonton Regional Palliative Care Program.
- Share educational and training resources, using videoconference, teleconference among others.
- Utilize consultation team model to share expertise and maximize resources.
- Share a regional on-call system if feasible.
- Recycle supplies and medications.
- Utilize electronic techniques to support patients and families in remote areas without opportunity for personal visits e.g., teleconference, videoconference, and telephone among others.

Challenge: To build palliative care content into core professional health education curricula and training programs.

The lack of palliative care content in professional health education curricula and lack of palliative care training for non-professional caregivers has negative implications for seniors who are at the end of life.

- Health care and social service providers in a recent study carried out in three Ontario nursing homes identified thirty-five topics in palliative care education.[37] Much palliative care is delivered by these providers working within a general practice, and in various care settings. As a result, educational preparation is often inconsistent.
- The Ontario Ministry of Health Palliative Care Initiatives is an exemplary education model. Funds are directed towards the community and long-term care settings to enhance the knowledge and skills of health care and social service providers who work with palliative care patients and families.[38]

Health care and social service providers working in rural communities are further disadvantaged in not being able to easily access educational opportunities or professional expertise.

- A pilot project[39] offering interdisciplinary training in palliative care to rural health teams from rural and Northern Manitoba offers a model for rural communities in other provinces.

Challenge: To eliminate fragmentation of end-of-life care delivery to seniors.

Fragmentation of palliative care delivery is manifested in many ways, such as the discontinuity of care planning that occurs when multi-service providers are involved in the senior's care. Fragmented care is very difficult, upsetting and confusing for seniors.

Recommendations:

- Establish adequate linkages between palliative care programs and other health care sectors[40] to promote the smooth transition of care from one health care and social service provider or setting of care to another.

- Develop shared documentation amongst health care and social service providers.
- Enhance communication and coordination of services by establishing a central administration for palliative care services.
- Develop admission criteria and collaborative linkages with other health care and social service providers to ensure that seniors are always referred to appropriate services.[41]
- Reduce duplication of services by region-wide, coordinated planning and evaluation of palliative care programs.
- Promote caregiver consistency by developing and utilizing specialist palliative care teams[42] for consultation purposes or the delivery of primary care.

Challenge: To address the ongoing underfunding and lack of resources accompanying the devolution of care from an institutional setting to the community.

- Community-based care can present special problems for seniors since most provincially-funded home care programs do not make provision for around-the-clock nursing care.
- There is often not a primary caregiver in the home, or the caregiver is also senior and may be suffering from chronic illness.
- Adult children may be geographically distant or unable for other reasons to assume a caregiving role.[43]

Recommendations:

- Federal and provincial policies and programs could be developed to minimize the financial costs of providing end-of-life care for seniors in the community.[44]
- Develop effective strategies and incentives to recruit and return health care and social service providers in home care programs.

Challenge: To enhance the appropriate utilization of end-of-life care by seniors.

Only a small minority of Canadians have access to palliative care, yet the prevalence of cancer and other life-threatening illnesses increases with age. Two-thirds of cancer deaths occur in persons aged sixty-five years and older.[45] A disproportionately high number of older Canadians receive end-of-life care in institutions. Home care, an alternative to institutionalization, is challenged to meet the needs of seniors who may lack adequate family support.[46]

Recommendations:

- The palliative care program should have a securely funded team, and have strong physician leadership that participates in decision-making at both the team and administrative levels. Different disciplines should identify themselves with the palliative care program and work collaboratively.[47]
- The palliative care consultation team, an efficient and flexible care delivery model, should be developed locally and utilized to support primary care teams, seniors and families in all settings of care. Regional palliative care consultation teams can effectively service outlying rural areas, offering telephone advice and support and/or direct care as appropriate.[48]
- Existing palliative care programs might consider collaborating in the development of this model.
- As more patient care shifts from the hospital to the community, home care agencies and long-term care facilities will need to ensure that training is adequate to help staff members cope with the ever-increasing complexity of patient care and cultural diversity of staff members, seniors and families.
- An alternative for home-based care, such as palliative care hospital beds, will likely continue to be necessary.[49]
- All health care and social service providers must be knowledgeable of available palliative care resources and inform seniors and their families of these care options.

- Home care resources and policies are required to enable seniors who have inadequate family and financial support to remain at home during the terminal phase of illness.
- Unnecessary and undesirable hospital admissions may be avoided if earlier discussions about advanced directives and preference for place of death take place between the health care and social service providers and the senior and family.
- The development and utilization of day hospice and palliative care volunteer visiting programs should be considered as supplements to home care services.

Challenge: To ensure that the institutional environment is therapeutic for seniors.

The atmosphere of an older patient's physical environment is part of the delivery of good palliative care. Institutional care can be noisy, lacking in space for privacy, disruptive by nature and sterile in appearance. This milieu may exacerbate the multifaceted problems faced by some seniors and their families.[50] Palliative care delivery requires a setting where the physical environment is conducive to therapeutic staff and patient/family interactions and where medical and other therapies can be integrated and complementary.[51]

Recommendations:

- An atmosphere that is home-like is achievable in almost any institutional setting. A family lounge, a patient suite where the family can remain overnight, a garden area, family access to a kitchenette, a quiet or meditation room, use of music and a relaxed dress code for staff are all examples of interventions conducive to a comfortable setting.

Challenge: To reduce the family's cost of providing care to their loved one.

Family members providing care to seniors in the home setting can experience significant financial, physical and emotional costs.[52]

Recommendations:

- Approved leave of absence from work with pay for family members.
- Early involvement of a palliative care team to identify needs, provide necessary support and make family aware of future options for care.
- Consideration of day hospice and palliative care volunteer visiting programs as viable options for family respite and for meeting the senior's needs for socialization and diversion.

Challenge: To promote timely referrals to palliative care programs.

Some members of the palliative care community have suggested that referrals to palliative care programs are appropriate at any point during the course of illness, not just in the final days or weeks of life.[53] Despite the benefits of early referral, palliative care programs usually receive later referrals. Reasons for this trend are multifaceted and widespread.[54] Members of the primary care team, especially the physician who often plays a gate-keeping role in the referral process, may not be aware of available palliative care services. There may be lack of acceptance within the senior's primary care team to accept the need for palliative care expertise or they may think that palliative care is primarily a nursing responsibility that focuses on psychosocial care. Additionally, team members may believe that if pain is being well managed, then quality palliative care is being provided, or wrongly assume that palliative care is a sub-section of oncology, resulting in missed referrals of seniors with non-malignant disease. Seniors and family members also play a role in avoiding or delaying referrals to palliative care.

Recommendations:

- Since it is not feasible to assume that all family physicians, nurses and other members of primary care teams will have, or maintain, an adequate knowledge base about palliative care without continuous high-quality education,[55] the education of all health care and social service providers in the core concepts of palliative care is essential.
- Recognize that the senior may experience pain and symptoms as a result of several co-existing conditions or illnesses and treat appropriately at all stages of the illness(es).[56]
- All health care and social service providers who work with seniors, including hospital clinicians and family physicians, need to have a shared understanding of available palliative care support.[57]

Delivery of care includes many different methods to deliver the same quality of end-of-life care. It is important for the senior who is receiving end-of-life care and his/her caregivers to know their options and to be aware that, as the illness changes, so may the delivery of care. However, the quality of care should remain a constant, always ensuring the senior and the family are the central care unit.

Health professionals working in palliative care and gerontology must continually promote awareness amongst government funders, policy makers and service providers for models of palliative care which will assure that all seniors in Canada have access to palliative care as part of end-of-life care.

CONCLUSION

Delivery of end-of-life care for seniors requires the collaborative efforts of many health care and social service providers working together with the senior and the family. It is important for seniors and their family members to know that they will receive the best end-of-life care that is available in the setting in which they are receiving this care. Seniors and their family members must also be assured that the delivery of end-of-life care will change as the illness changes. However, the quality of end-of-life care for seniors should remain constant in order to ensure that all seniors receive excellent care at the end of their lives.

It is also important that health care and social service providers who are working with seniors at the end of life be supported in the challenges of delivering this care. Many of the recommendations to meet the challenges associated with the delivery of end-of-life care for seniors have not yet been adequately addressed. Given the fact that our population is aging and that there will be an increasing number of seniors needing end-of-life care during the next 40 years, all of us as practitioners, educators, researchers and policy makers will have the opportunity to make a significant difference in the provision of excellent end-of-life care for seniors.

SUMMARY RECOMMENDATIONS FOR PRACTICE

- Ensure that the philosophy and principles of palliative care are integrated in the care of seniors who are dying, whatever the setting.
- Assist seniors and families to choose the setting for care that is most appropriate to their needs and capabilities.
- Strive for continuity of care that minimizes duplication across settings and providers from admission of the senior to the bereavement period for the family.
- Ensure that optimum end-of-life care services are available to all.

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chapter 6

CARE FOR THE CAREGIVERS

INTRODUCTION

Goals of this Chapter are to:

- provide an understanding of who the caregivers are and what their support needs are
- provide an understanding of the 'caregiver burden' and all that it encompasses
- emphasize the importance of providing care to the senior and the caregivers as a 'unit'

> *"There are only four kinds of people in this world - those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who need caregivers"*[1]

Delivery of end-of-life care is important for the senior who needs such care. Equally important, though, is the care for the oft-overlooked caregiver who will often have an increased workload and increased stresses, and yet may have little support by other family members and health care and social service providers. It is important that these caregivers are supported, not only to help make their workload manageable, but to provide the opportunity to make an incredibly emotional and stressful event as positive as it can be.

Caring for seniors at the end of their lives can be a stressful, but sometimes rewarding experience[2] for their family members. There are many rewards inherent in family caregiving for seniors such as:

- opportunities to demonstrate love and affection for the older family member
- potential for family enhancement
- improved relationships with siblings and other family members
- increased family cohesiveness
- altered perception of life's meaning
- personal growth[3]
- times of incredible intimacy that may come from caregiving and from facing death

> *"Caregiving is about you and me - it's about all of us. Sometime during our lives, whether we're the caregiver or the one cared for, there will likely be an opportunity to explore the possibilities of transforming an unforeseen hardship into hope, to discover the incredible rewards and unexpected harvest in the act of caregiving."*[4]

There are also considerable challenges for the family caregiver who is caring for older family members at the end of life. This chapter will discuss issues related to who cares for seniors at the end of their lives, the concept of caregiver burden, the caregiving process, interventions for caregivers, grief and loss and the stress of the professional caregiver.

WHO CARES FOR SENIORS?

- According to Statistics Canada, about 2.1 million Canadians are caring for senior relatives either in their own homes or the senior's home.[5] As much as 90% of care provided for Canadian seniors in the community is provided informally.[6] Frail, terminally ill seniors require one person's full time commitment to co-ordinate care and be present at night as well as regular home visits from the physician, the nurse, and other health care and social service providers.[7]
- Within institutions, 30% of services are provided by informal networks.[8]
- Two factors determine who is most likely to provide informal care - **gender and age**. Females are most likely to provide care. The estimates range from 60% - 75% of eldercare in Canada being provided by women.[9] Caregivers are often the older spouse who may also have health problems and daughters, particularly the eldest daughter.[10] Most of the woman caregivers have other jobs and 25% were also looking after children under the age of 15.[11] The age of primary caregivers tends to be between 52-84 years. A large proportion of the female caregivers are 60 and over, with an average age of 73 years. Married men represent the oldest group of caregivers.[12] There are three typical patterns of caregiving based on age: the youngest age categories are adult children providing assistance to a dependent parent; among spouse caregivers, women are younger than men; and women caregivers with children of their own are older than are men in the same situation.[13]

Why are women the primary caregivers?

- responsibility for caring and concern for others is seen as central to women's identity[14]
- the caregiving role may be thrust upon women through the structures of society such as relationships between the generations, and between men and women
- the limited availability of public services
- the fact that men do not feel as responsible for assuming caregiving activities within the family
- women's feeling that the responsibility of family caregiving rests with them[15]
- women live longer in better health than men

Adult children as caregivers:

- Among adult children caregivers, approximately 70-80% of care is provided by daughters.[16]
- As age and frailty increase, seniors are more likely to live close to adult children.
- Daughters are more likely than sons to provide "hands on" assistance and daily help with homemaking, personal care, home health care, transportation and psychological support.[17]
- Sons are more likely to provide help with home repairs, handling finances, home maintenance and contacting organizations.[18]
- Siblings who can work together in providing support to their aging parents may develop increased closeness through increased interaction that may lead to support and companionship into their old age.[19]
- "Caregiving changes the parent/child relationship as the dependency roles change, and the adult daughter in particular may be forced to revisit old conflicts with parents with the parent who is now in need of care".[20]
- Recent work in Saskatchewan indicates that approximately 20% of employees in that province spend time each week looking after children and older dependents.[21]

Seniors may have more difficult access to informal care than younger patients for various reasons:

- spouses may have health problems of their own
- lower income due to retirement

- children may have families of their own
- family members may live far away
- friends may be older and unable to provide support[22]

However, much of the care for seniors at the end of life is provided by family members. Most of this care is provided by spouses (primarily wives) and daughters or daughters-in-law. This means that health care and social service providers must:

- be aware of the family caregivers' struggles in providing care for their family member at the end of life
- try to support these family caregivers in any way possible
- be aware that women are the main caregivers of seniors

BURDEN OF CARE

Caregiver burden is "the emotional and physical demands and responsibilities of one's illness that are placed on family members, friends, or other individuals involved with the patient outside of the health-care system".[23]

The concept of "burdening" is one of the major components of the palliative care experience.[24] Caregiver burden involves the impact that living with a senior has on the way of life and health of his/her significant others.[25] This burden can have many significant consequences such as caregivers ignoring initial symptoms of their own failing health[26] and not seeking medical attention until after the senior's death.[27]

- Already strained relationships within families may be tested further as an older parent approaches the end of life.[28]
- Financial difficulties relating to medical costs, reduced income, disruption in employment and higher living expenses often present difficulties.[29]
- Multiple caregiving roles may negatively affect the caregiver's well-being[30] and in fact, the needs of the caregiver may exceed those of the senior.[31]

A wife who was caring for her husband in the last stage of Alzheimer disease stated: "I had to occupy him. This was the worst part of it. I found that I had no life. I finally didn't think of anything else at all but Alzheimer's. Everybody was giving me papers to read and all this, and I said 'I don' t need this. I'm living it.' He's not worried about anything. I do. I'm worried every hour. I'm the one who seems to be sick."[32]

- More than half of caregiver exhaustion can be predicted by three factors: lack of personal time, being employed in a job outside the home and frequent behaviour problems of the care recipient.[33]
- Caregivers need better support than they are currently receiving. It is important to recognize that there may be a mismatch between professional caregivers' assessment of burden and that of the family caregiver.[34]
- Caregivers often have a reluctance to use existing respite services.

The factors affecting caregiver burden are complex, involving developmental and cultural factors, in addition to the stressors of the illness itself as well as the caregiver's gender, coping style, social network and the caregiver's level of intimacy with the elder.[35]

EMOTIONAL DISTRESS

Caregiver Burden

Caregiver burden is more likely to affect mental health than physical health or financial outcomes.[36] A spouse caring for her husband who was receiving palliative care services stated:

> *"What was the worst part of the whole situation? It's not that I was exhausted physically, because you can be, obviously. Or not having a moment to myself or not being able to just go for a walk for two hours without feeling guilty about it. The worse part was how emotionally drained I was."*[37]

Depression has been found to be higher among caregivers than in the general population,[38] and more specifically, higher among women who are a disproportionate percentage of the caregiving population.[39]

- Depression in well spouses during the final illness has been associated with the functional status of the terminally ill spouse[40]; the patient's depression[41]; whether the well spouse quit work as a result of the partner's terminal illness[42]; and depressive symptoms during bereavement.[43]

Untreated depression may lead to psychological difficulties within relationships with spouses and friends, enjoyment of leisure activities, general social adjustment, and overall contentment.[44] These symptoms and resulting behaviours can affect the quality of life for both the caregiver and the care recipient, as well as the continuity and quality of care provided to the senior who is disabled.[45]

- The needs for care of older frail seniors have been related to greater risk for depression in the caregiver indirectly through the hours of care provided and the caregiver feeling overloaded.
- Caregivers with a high level of mastery or emotional support are at lower risk of depression.
- Daughters are found to have more emotional strain than sons when caring for older frail parents. For daughters, the most important predictors of emotional strain were interference with work and quality of relationship with the parent. For sons, the most important predictors were behavioural problems of the parent and few informal helpers.[46]
- In 1996, 29% of caregivers of persons with long-term health problems stated that caregiving had altered their sleep patterns and 21% claimed their health had been affected.[47]
- Elder abuse has become a problem. It can occur as: passive neglect, active neglect, physical abuse, psychological abuse, material or financial misappropriation, violation of rights, self-abuse, and self-neglect.[48]
- Caregivers who may be at risk of abusing are those who already have other caregiver burdens such as an alcoholic spouse or delinquent child; those who live in overcrowded dwellings; face economic hardships, have a history of intergenerational conflict and/or are otherwise dysfunctional.[49]

Work-home conflict:

- About half of caregivers reported that caregiving had repercussions on their jobs (lateness, absenteeism).[50]
- One recent study found that "one third of employees who provided care to both children and elderly family members...found it very difficult to balance paid work and home responsibilities".[51] A daughter who was caring for her mother who was dying stated:

> *"We also have (jobs), many of us are taking vacation days, we're taking stat holidays. I, myself, am choosing not to work in this period...We give pregnancy leave...we give paternal leave for the father to bond with his child, but when, at the other end of the spectrum, when people are dying, why don't we give caregiver relief?"* [52]

Needing to alter work hours is associated with higher stress in caregivers.[53] High work-life conflict is associated with:

- decreased wellness including greater perceived stress, depressed mood and burnout; and poorer physical health
- reduced job satisfaction and organizational commitment
- greater use of the Canadian medical system (i.e., increased number of physician visits, increased illness)
- increased absence from work[54]

Canadian caregivers with a high work-family conflict were absent from work an average of 13.2 days compared with those who reported low level of conflict (5.9 days). What does this mean financially? A $**2.7 billion** cost involving time off to deal with dependents and to deal with stress and illness caregivers encounter from their juggling act. A $**425 million** cost to health care system of 86.9 million extra visits to physicians.[55]

FINANCIAL BURDEN*

The care provided by families is not free. The cash value of services provided by families far exceeds the combined cost of government and professional services to both seniors who live in the community and those who live in institutions.[56]

- Caregivers also incur "invisible" expenses, including home modifications, rented equipment, special foods, higher heating bills, and the "opportunity costs" of caregivers who forgo paid employment. This type of family support is estimated to be the equivalent of full-time work in about one-third of households providing elder care.[57]
- Quality care in institutions can easily cost thousands of dollars per month.[58]

Therefore, family caregivers experience a great deal of hardship in meeting the challenge of caring for older family members at the end of life. This hardship is generally in the form of physical exhaustion, emotional distress and financial difficulties. This means that health care and social service providers must:

- be aware of these stresses on the family caregiver
- offer support in any way possible from the resources that are available
- advocate for the development of new services and encourage their use

THE CAREGIVING PROCESS

Differing disease patterns and levels of support are likely to have a major impact on the level of stress a caregiver experiences.[59] The family's response to illness will in part be determined by whether the illness comes out of the blue with no warning, or whether they have time to adapt to changes.[60] Families begin to develop their own timelines at the time of diagnosis. Discussions about the nature of the illness, its prognosis and prescriptions for management constitute a 'framing event' for families.

ALZHEIMER DISEASE AND THE DEMENTIAS AFFECT CAREGIVING*

Caregiving trajectory

- Gradual recognition that something is wrong
- Intensive home care and beyond
- Initial phase: Demands may be quite limited and easily incorporated into life.

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*Additional information on this topic is in Chapter 2.

- Mid phase: Demands become more difficult.
- Later phase: After person may have been placed into a formal institution, caregiver frequently continues to provide supplemental or "invisible care."[61]

The most common reason for admission to hospital or hospice is a breakdown in the ability of the caregiver to continue providing the level of help required to allow the person to remain at home.[62] Caregivers in this situation tend to experience a decrease in caregiving role; a decreased role in caregiving; a decrease in role overload; a decrease in symptoms related to anger; an increase in guilt; and an increase in socioemotional support.[63]

Organization of Stressors in the Lives of Caregivers: Primary and Secondary

The primary stressors of caregiving (the stressors caused directly by caregiving activities)

- Primary stressors are the conditions, experiences, and activities that are problematic for people, threatening them, thwarting their efforts, fatiguing them, and defeating their dreams.[64]
- Stressors have the ability to arouse stress which manifests itself as tension, uneasiness, anxiety, alarm, worry, fear, dread, upset, and physical illness.[65]
- Cognitive impairment, functional disability, and the presence of problem behaviours[66] in the care recipient are linked to the hours of informal care provided to the senior[67] which relates to primary stressors.
- Role overload: Caregivers to family members with progressive dementia are more distressed than the general population.[68] Some difficulties of family caregivers of people with Alzheimer disease are seen from these statements by daughters caring for their mothers:

> *"After a year, I just couldn't do it. Like, she would go to bed as six or six-thirty at night and I couldn't. So at five or six o'clock in the morning, she'd be knocking at the door, 'Are you all right?'---'Yes, mother' "; "I would just encourage people who have Alzheimer's patients to put them in a home because it's very hard to take care of them. Very hard. Even to eat, they're slow to eat, even your own eating is disturbed, your whole life is disturbed."*[69]

- Role captivity is the sense of being trapped in the role as caregiver when one would prefer to be doing something else. The distinguishing characteristic is not that the role is difficult or stressful, but that it is unwanted.[70]
- Caregivers may come to feel that their spouse or family member has disappeared as cognitive abilities decrease, leaving this stranger with the same physical characteristics to be cared for. They may also have a fear of not being able to handle symptoms.

The secondary stressors of caregiving (the stressors caused indirectly by caregiving)[71]

- Over time, primary stressors may generate secondary stressors such as a diminished sense of self that may continue even after the senior's death.[72]
- The care-related stress may have an impact on other social roles such as parent, spouse or worker and may create a diminished sense of self in the caregiver.
- Social support and mastery, that is maintaining a positive view of one's ability and behaviour during the caregiving process, may help to minimize secondary stressors.

Three major themes are related to undertaking the caregiving role.[73]

- Life restrictions: This role combines events and activities impinging on the caregiver's own life. Younger caregivers have particular difficulty with these restrictions.

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* Additional information on this topic is in Chapter 3.

- Emotional consequences: Caring for a dying family member or friend is clearly stressful and a number of caregivers may have difficulty with the situation. Worries about the future are common. Communication is often difficult, but sometimes families may become closer to the senior or to other family members.
- Support received: Family and friends are relied on most often, although help may not always be sought even if it is available. Self-reliance and independence are valued by caregivers and they are hesitant to place additional demands on family and friends. This can lead to caregivers' often feeling quite isolated in terms of emotional support. However, the support of health care and social service providers is usually appreciated.

ANTICIPATORY LOSS AND GRIEF IN CAREGIVERS

Anticipatory loss involves a range of intensified emotional and interactional responses over the course of the illness. Anticipatory loss includes the mutual influence of family dynamics with:

- family members' threatened loss of the ill member
- ill member's anticipation of losing his/her family
- ill member's expectation of disability and/or death

Threat of loss encompasses:

- the "person"
- the relationship with the ill senior
- the intact family unit

Anticipatory grief refers to individual emotions during the terminal phase.[74]

INTERVENTIONS TO DECREASE THE STRESS OF CAREGIVING

Recognizing Signs of Caregiver Burnout:

- Denial about the disease and its effects on the person: "I know Mom will get better"
- Anger at the affected person: "If he asks me that question once more, I'll scream"
- Withdrawing socially, losing touch with friends and favourite activities
- Anxiety about facing another day and what the future holds
- Depression, feeling sad and hopeless much of the time
- Exhaustion such that completing daily tasks seems barely possible
- Sleeplessness with middle-of-the night waking or stressful dream.
- Emotional reactions such as often being irritable, crying at minor upsets
- Lack of concentration and finding it difficult to complete complex tasks
- Health problems, including weight gain or loss, chronic headaches or backaches[75]

Ways to Help Prevent Caregiver Burnout:

- Plan early to find ways to support yourself to stay healthy through diet, exercise, vitamins and supplements, yoga, meditation, time for yourself.
- Take time off to pursue some interest or hobby.
- Take advantage of offers for help from family, friends and community agencies.
- A caregiver who does not take care of him/herself is not much good to his/her loved one. "Do things that bring you joy and keep you going...You need to balance everything so that you can find the equilibrium that gives you energy for things you'd like to do as well as the things you have to do".[76]

- Be patient with yourself, recognizing that some days are going to be more difficult than others, but maybe tomorrow will be better.
- Try to think of at least one good thing that happened today.
- Have at least one person you can confide in who can give you support and to whom you can provide support as well in a mutual relationship.
- Spirituality can provide support.
- Maintain contact with others in a similar situation through support groups.
- Get information about resources available through the Alzheimer Society, the Canadian Cancer Society or other community resources and take advantage of what is out there.
- Realize there may well be a time that you will be unable to continue to care for your loved one at home and you need not feel guilty about this.[77]
- Try to get enough rest.

Ways Health Care and Social Service Providers can Help Prevent Caregiver Burden:

- Focus on the contribution to caregiver overload and intervene to prevent overload, rather than simply relieving it.
- Develop strategies to prevent overload by training caregivers in technical skills or in obtaining emotional support before they actually need it.
- Create supportive, educational approaches to develop skills, empower caregivers, and reaffirm their existing skills, abilities and knowledge.[78]
- Provide emotional support as an intervention as higher levels of emotional support may decrease depression.
- Evaluate the health and disability of the care recipient and determine the level of care needed.
- Determine the resources available to support the caregiving process.[79]
- Encourage caregivers to develop skills to elicit desired emotional support from family and friends.[80]
- Provide caregiver education and assistance.
- Use therapy and concrete problem solving.

It has been suggested that the reason for the reduced quality of the relationship between caregivers and seniors with Alzheimer Disease is the loss of their relationship with the loved one.[81] The period of actual caregiving may not be the time for intervention. This may be the period of grieving the relationship loss.

Needs of the Family:

- to adapt to the fact that their loved one is dying
- to mourn for the senior and for the loss of their family as it exists
- to reorganize and restructure family roles and functions and to plan for the future
- to attend to the needs of individual family members, bearing in mind age, health status, maturity, coping skills and the nature of the relationship with the dying person
- to care for those of the group most closely involved with the senior's care
- to gain information about the illness, the treatment options and what they can expect from the caregiving system
- for practical assistance with such things as housekeeping chores, finances, respite, finances, advocacy
- to plan for the funeral and burial
- to say goodbye to their dying loved one
- to have someone really listen to their concerns and fears, and to acknowledge that these may be difficult to express[82]

- to understand the disease, its possible causes, and options for its treatment
- to learn how to deal with symptoms

Suggestions for Family Members Considering Placement:

- Do as much planning as possible. Waiting lists can be long and when the time comes for a move, you want to choose the best residence or other facility that you can.
- Ask someone in the health system who knows what community facilities are available to steer you in the right direction.
- Get the paperwork and planning out of the way as soon as possible. Visit the facility ahead of time to make the unfamiliar familiar. Ask for a facility tour.
- Be frank when it's time to acknowledge that you cannot provide the care that is needed. Try to focus on the senior and everybody else involved, and talk honestly about it.
- Involve other family members so that all stressful decisions do not fall to you.
- When you come home after placing your loved one, have someone there to talk and share your grief.
- Identify potential financial and legal issues, e.g., dealing with Power of Attorney for finances and personal care; making decisions regarding end-of-life care and when to intervene.[83]

Advantages of Dying at Home:

- A familiar environment can result in increased psychological comfort and reassurance, resulting in an improved quality of life during the terminal stage.[84]
- Family caregivers may be better able to maintain family ties, reduce feelings of guilt and cope better with the eventual bereavement.[85]

BEREAVEMENT AND GRIEF*

Three closely related components make up the bereavement process: loss, grief and recovery.

- Loss: the separation from a part of one's life to which one was emotionally attached
- Grief: the complex emotional, cognitive and perceptual reactions that accompany loss. It involves the painful separation from someone or something we have loved very much, and it hurts deeply. Grief may occur before death as well as after death.
- Recovery: the final component in surviving the death of a loved one and finding meaning and purpose in life after the death. While time may help to heal the wounds left by death, in recovery what really counts are the circumstances with which survivors must deal as time goes by: the nature of the losses one has experienced, the social and economic resources upon which one can call, and the ability to restructure one's life.[86]

Loss, grief and recovery may not be independent of one another. Each may emerge very slowly and never completely displace the stage that came before it.

The immediate impact of the death

The length of time spent caregiving allows for considerable forewarning of death and thus, there is the possibility that psychological and social preparation may lessen the impact of the death and its consequences.[87] However, not everyone facing a death from a long-term illness has faced the fact that death will come eventually. Despite having expected the senior to die, there is often a stage of shock and disbelief when death actually occurs.

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* Additional information on this topic is in Chapter 8.

Mr. S. died suddenly after years of ill health. As his family was sitting around the dining room table between visitation services at the funeral home, Mrs. S got up and left the table. She quickly returned to her seat, a somewhat puzzled expression on her face. She spoke to her large family of adult children and said "I was just going upstairs to say to your father isn't it nice all the food people brought in for your wake."

At the time of death, family members may feel numb, confused, bewildered and even completely abandoned. Fears as to how to cope with the next few days and the future may be overpowering. There may be a sense of relief if the death has been a long time in coming and/or if there has been a considerable amount of suffering for the senior as well as family members. This feeling of relief may in turn lead to feelings of guilt.

While nothing can take the pain of grief away, some families find comfort in believing that their loved ones are going to another place and that they will see them again. For some seniors, there is a sense that their grief will not go on forever. Even if they don't believe in an afterlife, some derive a sense of relief in knowing that they will die within the foreseeable future.

When the death is difficult and family members are left to struggle with wishing symptoms had been better handled, there had been a better sense of closure, they had been present, or there is unresolved guilt, dealing with grief can be difficult.

THE PHASE OF ACUTE GRIEVING

Mrs. P. had cared for her husband for years. The first time she went to the grocery store after he died, she quickly finished her shopping and brought her cart to the check out line. The line was long so she left her groceries to rush home to her husband, only to realize a couple of blocks from the store that she no longer had to rush home to be with him.

This will generally be a very difficult time. Caring for the deceased senior may well have previously provided the structure around which all of one's activities revolved. This phase may last for several months. It is the time during which the grieving family members grow to accept psychologically that the person has really died. Feelings may come in waves and can create distressing physical effects, as well. The bereaved person may withdraw from social interactions and be preoccupied with the person who has died.[88]

There will be business issues to attend to in the first few week, e.g., getting death certificates and notifying those who need to be informed. Family members could be encouraged to get support during this period because there are several difficult activities to take care of such as dealing with insurance companies, pension plans, writing notes to those who sent flowers or donations, among others. There may need to be decisions made regarding whether living arrangements need to be changed. Generally, one should not make any major moves for at least a year after bereavement; however, health issues may lead to concerns about whether an elderly spouse should continue to live alone and if not where might he/she live? If a move is necessary, that may lead to new feelings of loss and grief.

Signs and Symptoms of Grief

- Feelings: sadness, anger, guilt and self reproach, anxiety, loneliness, fatigue, helplessness, despair, shock, yearning, emancipation, relief, numbness, depression, emptiness

- Physical sensations: hollowness in the stomach, tightness in the chest, tightness in the throat, oversensitivity to noise, a sense of depersonalization (a feeling that one is not really oneself), breathlessness or feeling short of breath, muscle weakness, lack of energy, dry mouth
- Behaviours: sleep and appetite disturbances, absent-minded behaviours, social withdrawal, dreams of the deceased person or of death, avoiding reminders of the deceased person, searching and calling out, sighing, restless overactivity, crying, visiting places or carrying objects that remind one of the deceased person, treasuring objects that belonged to the individual
- Cognitions: disbelief, confusion, preoccupation, sense of presence, hallucinations, thoughts and memories from the past, efforts to maintain or to separate from the deceased senior, dissociation (feeling internally disconnected)[89]

Grief in seniors may be complicated by the fact that many of their friends and relatives are also aging and may be sick and/or have died. Their social circle may be shrinking which adds to their experience of grief. In contrast, some of their friends may be enjoying healthy retirement years as a couple. This may lead to feelings of jealousy, which may be difficult to acknowledge.

- Among the general population, depression, sadness, and grief increase in the months right after death and then decline.[90]
- By the second year of bereavement, the level of depression is similar to that found among the non-bereaved.[91]
- Various grief responses, such as thoughts and feelings about the deceased and yearning for the deceased, continue well beyond the first few years.[92]
- The demands of the caregiver role can lead to frustration, ambivalence, and guilt which might complicate bereavement.[93]

The bereavement experience after caring for a family member with Alzheimer Disease:

- During the first year of bereavement, caregivers are generally less distressed than during the earlier stage of home care. Once caregiving stops, there is a dramatic decrease in feelings of being overloaded. However, other ongoing stressors and psychological stressors change very little during the first year of bereavement.[94]
- However, in caring for someone with Alzheimer Disease, there may be the sense that the person for whom one is caring has been lost before the death actually happens and this can serve to decrease the distress that might otherwise have been associated with bereavement.[95]
- Those who had more family strain during the caregiving period had more family strain during the bereavement period.[96]
- The more hands-on caregiving involvement caregivers had, the more depressed they felt following the death. Very involved and committed caregivers may experience major changes and disruption in the pattern of their lives with the death and this can be associated with depression.[97]
- Caregivers in better health felt less overloaded after death, as did those who experienced more difficult behaviour on the part of the care recipient.[98]
- Spouses were found to be no more distressed or grief stricken than adult children who lose their parent.[99]

Restitution phase

This phase centres on recognition of what the loss means to the bereaved caregiver:

- loss of the many roles the senior fulfilled - spouse, parent, friend, lover, bill payer, cook, homemaker, carpenter among others

- what are the other losses that will come from this loss - change in financial situation, need to move, recognition of the finality of death, concern about hereditary diseases, concern about abandonment
- recognition that one has grieved, and now it is time to shift attention to the outside world; memories and loneliness are a part of that world, but the deceased senior with his/her illness and problems is not
- One is moving on when one is able to recognize that one has grieved and is now ready to return to normal activities, reexperience pleasure in life and interact with and feel love for others.[100]

WIDOWHOOD

Gender differences

Females:

- have higher distress and depression rates and have more visits to their doctors[101]
- can generally express their emotions more easily in grief
- are more likely to seek social support[102]

Males:

- have higher death rates - through suicide, circulatory diseases, accidents, alcoholic cirrhosis[103]
- have risks associated with grief, not only in the early stages; the state of widowerhood is a long-term problem for a man[104]
- are more likely than widows to have physical health problems[105]
- living alone have more psychological distress than those living with another person, usually an adult child[106]
- generally find it easier to avoid confronting their feelings and turn instead to distracting activities, dealing more with the practical problems that occur with bereavement, rather than with the feelings it evokes[107]
- are less likely to talk about their loss, seek social support, or talk to others compared to widows[108]

Why the gender differences?

- For males, their wives are often their main and only confidant. They may be more socially isolated with dire consequences.
- Females are more likely to have other people, usually women, in whom they can confide.[109]

Who is at risk for depression?*

- Depression is generally associated with poor social support; prior psychiatric history; unanticipated death; other significant stresses or losses; high levels of initial distress with depressive symptoms; history of alcoholism[110]; lower socioeconomic status[111]; language barriers[112]; and depression earlier in the person's illness.[113]
- Widowers who avoid doing grief work were more depressed later in bereavement than those who confronted their grief.[114]
- Those who had past conflicts in their relationships had increased guilt following the death.[115]
- During bereavement caregivers look back over their family and caregiving histories and confront past resentments, inadequacies, and ambivalence.[116]
- Those who found caregiving difficult were more likely to find bereavement difficult.[117]

What helps prevent depression?

- practical preparations made before the final illness[118]
- involvement in hospice programmes for the person who has died and participation in a bereavement programme for the caregiver

* Additional information on this topic is in Chapter 3.

- extensive after-death support[119]
- a prior sense of mastery, an already developed sense of the loss of the care recipient, and a past difficult relationship with the care recipient[120]
- having financial resources[121]
- a social network, support from family and friends, personality, spiritual beliefs, socioeconomic status, personal health status and support groups

Once caregivers regain a sense of being in control, they may come to think more positively about themselves.[122]

Factors Associated with Major Depression in Bereavement

A diagnosis of Major Depressive Disorder is generally not given unless symptoms persist for two months after the loss or include:

- guilt about things other than actions taken or not taken by the survivor at the time of the death
- thoughts of death other than the survivor feeling that he/she would be better off dead or should have died with the deceased person
- morbid preoccupation with worthlessness
- marked psychomotor retardation
- prolonged and marked functional impairment
- hallucinatory experiences other than thinking that he/she hears the voice of, or transiently sees the image of, the deceased person[123]

Medication for grief is best used in combination with psychotherapy and for a limited time. Anxiolytics, most commonly the benzodiazepines, can be used during the early weeks of grief for insomnia. Daytime use decreases the feelings of tension, anxiety and irritability. The vegetative symptoms of depression, particularly insomnia and agitation, can be alleviated with an antidepressant.[124]

- The use of antidepressants can also improve sleep quality in those with depression. Sleep efficiency and sleep quality have been found to continue to improve after the discontinuation of antidepressants coincident with clinical remission of depression in bereaved seniors.[125]

HEALTH CARE AND SOCIAL SERVICE PROVIDERS

Sources of Stress in Chronic Care and Palliative Care Settings[126]

Team communication challenges have generally been found to be among the biggest sources of work stress in a number of studies of those working with the critically ill, chronically ill and dying.[127] A lack of support from one's team members was implicated in high levels of depression.[128]

Role ambiguity involves not knowing what one's role should be. Caregivers who care for people for a long time may develop very close relationships which go beyond traditional professional roles. Such close relationships are often encouraged in palliative care settings. Sometimes there can be problems when professional and personal boundaries blur.

Identification with patient and family involves staff members identifying with certain patients and family members who remind them of someone from their past or with whom they share a special bond. There can then be feelings of loss and helplessness when these patients deteriorate or die or when staff empathize with the feelings of the family and have difficulty witnessing their pain and suffering. If dying seniors are distressed, caregivers may feel helpless because of the expectation that the current availability of drugs should be able to handle pain or distress. Nurses on ICUs reported difficulty with the unexpected turn of events when patients who were expected to get well suddenly took a turn for the worse. They found it difficult not to be able to organize and control events related to withdrawing active support and moving to comfort measures. They wanted to be able to give the family time to come to terms with the change of plans, but at the same time, they did not want to unnecessarily prolong the suffering. They had trouble when they could not predict the timing of the death, particularly if family members left and the senior died.[129]

Seniors and families with coping and/or personality problems

- The behaviours of residents with dementia can cause difficulty in daily contacts between nurses and residents.[130]
- Seniors and families who respond to their illness in a way that differs from the norm may present problems to staff members. This group includes seniors or families who became extremely depressed, angry, withdrawn or psychotic; those who completely denied what was happening; those who acted out by drinking or taking drugs; and those who engaged in avoidance behaviour.[131]

Communication challenges with patient and family

Dealing with demented residents and their concerned family members can sometimes present challenges to caregivers.

- Levels of perceived involvement in decision making may influence the quality of staff-resident interactions in residential settings.[132]
- Education and improved support from colleagues can also improve interactions.[133]

Role conflict

Role conflict in palliative care can evolve when one's role as a team member is in conflict with what one thinks is in the best interest of patients. Such issues include:

- working with seniors who may not yet be ready to accept the reality of impending death, when the health care and social service provider feels it is time for them to stop aggressive treatment[134]
- 'allowing' patients to maintain control, while feeling disappointed in not being able to fully discuss patients' expressed wishes to die
- taking actions to help seniors or families maintain a sense of control, while questioning the wisdom and morality of their decisions
- dealing with the sometimes hazy distinction between patient autonomy and a professional ethic of care[135]
- deciding to transfer patients from active treatment settings to hospice and/or palliative care programs, primarily for economic reasons[136]
- dealing with cutbacks in health care resources

Communication challenges among health care and social service providers

- Tension can arise among health care and social service providers with differing views of palliative care.[137]
- Some long-term care facilities attempt to integrate hospice teams from another setting leading to "turf" or "territorial issues". Hospice teams and long-term care staff members must work closely together to have common goals, educate one another regarding the similarities and differences in their philosophies, deal with issues of role overlap, and develop treatment plans reflecting the needs of the senior and the family.[138]
- A lack of participation in planning and decision-making have been associated with depression and increased stress.[139]

Characteristics of End-of-Life Care for Health Care and Social Service Providers

Health care and social service providers experience daily emotional stress as a result of being confronted with the deaths of seniors or their severe illnesses, with seniors who are mentally impaired, their loneliness and failing health.[140] Sources of satisfaction from palliative and chronic care include:

- valuing each individual, experiencing the reciprocity of giving and receiving in relationships, a sense of interconnectedness, and of mutual nurturing, being close to seniors and sharing a part of one's self; the chance to make a difference in people's lives[141]
- helping seniors achieve optimum health by enabling them to do all they are capable of doing; being able to give patients options, recognizing that patients are the directors of their own decision-making; being able to personalize the hospital environment so patients can feel more at home[142]
- assisting patients and families to learn to cope with and adjust to caring for a dying relative at home, death at home, learning from patients and families[143]
- experiencing positive feedback from patients and families, effective relating with and communicating with patients and families[144]
- witnessing the smooth termination of life, initiating innovative, effective intervention for the patients, the right decision at the right time, peace for the patient[145]
- being able to provide families with good memories in the midst of difficult times[146]
- helping patients to find meaning in suffering[147]
- an opportunity to learn skills and to develop as a person; the ability to constantly learn[148]
- relationships and support from colleagues[149]

Grief Overload

Constant exposure to death and loss may leave health care and social service providers with grief overload and considerable distress. However, participating in the death of some seniors may result in health care and social service providers' having intense positive responses that promote professional development.[150]

- Constant confrontation with the deaths of others causes these providers to repeatedly re-evaluate their own mortality and to re-examine the meaning of their life and living.[151]
- Health care and social service providers have difficulty with grief if they have not been able to help the senior die a good death for whatever reason.[152]
- When the symptoms of dying patients are not controlled, the health care and social service providers feel responsible, and 'wanting' and, if training and experience are lacking, this may well be the case.[153]
- Staff members often experience difficulty dealing with their feelings of grief and loss at the time of death because of other responsibilities that must be attended to immediately. There is often a strong covert institutional message as well as peer pressure not to dwell on the loss.[154]

Coping Mechanisms[155]

Learning how to strike the fine balance between retaining emotional distance and becoming emotionally involved with residents' problems and concerns can be a challenge. On the one hand, staff members have to adhere to the rules of an organization including values such as efficiency, perfection, distance and a business-like attitude. On the other hand, they have to meet the human values inherent in health care such as continuity, empathy, well-being, helpfulness, love and affection.

Some health care teams favour organizational values:

- Standardization in which residents are all treated equally. There are fixed rules, routines and procedures.

Activities and responsibilities are written down, planned, scheduled, and divided among the health care and social service providers. Each provider carries out one part of total patient care. Consequently, seniors have to deal with many different providers. The combination of these two tactics leads to health care and social service providers treating all residents in the same way, thereby restricting personal contacts or the expression of feelings.

- Normalization ignores the impact that serious mental and physical handicaps have on residents. Staff members act as if residents were still at home, continuing their normal daily patterns. Tactics include minimizing health problems, covering up limitations and masking visible handicaps.
- Avoidance strategy is employed to reduce the anxiety and tension experienced between emotional distance and involvement. Health care and social service providers who use this strategy tend try to avoid intensive communication, situations and activities which demand sympathy and identification and which can therefore, cause feelings of tension and fear.

Some nursing teams use strategies that tend to favor the residents' needs:

- The consultation strategy involves settling problems by consultation and establishing priorities by mutual agreement. Health care and social service providers meet to divide tasks among themselves and to search for solutions to problematic situations. In this way, workload is reduced. In the consultation approach, each team member stands up for his/her view and works to find solutions. Each person listens to the others and there is a freedom for each team member to care for residents in the way they see fit within the rules of the organization.
- The acceptance strategy involves making the care provided towards residents' health and daily lives realistic and appropriate. This strategy recognizes that residents' illnesses and impairments have fundamental consequences for their daily lives and communication with others. Team members accept that residents are not going to recover and their job mainly involves giving residents as pleasant a time as possible in the nursing home. The acceptance strategy aims to fit the needs of the residents, rather than forcing upon them rules and expectations which they are unable to meet because of their health status.
- The dosage strategy establishes a balance between distance and involvement in the relationship with residents. Health care and social service providers often say that they did everything possible for a senior or that a senior who was in considerable pain is better off now that he/she is dead. They use these statements to control their emotions in difficult situations, so that they are not overwhelmed at critical times. This enables them to continue to provide care even at difficult times on the ward.
- At times, multiple losses can lead to a sense of grief overload that may need to be dealt with in a variety of ways including: memorial services, journaling, staff 'wakes', attending a funeral, sharing with the family of a client the joys the person brought into one's life, or the lessons that one will always remember from this person. At times, it may be helpful to attend the funeral of one patient but to use it as an opportunity to reflect on the deaths of more than one person.[156]

CONCLUSION

Caregivers play a significant role in the delivery of end-of-life care to seniors. The role involves many challenges, often placing quite a burden on the caregiver. On the other hand, many caregivers have found it to be a rewarding and spiritual experience. Whatever the caregiver's experience, it must be recognized by health care and social service providers that these family caregivers need both physical and emotional support in order to continue to provide good care. This will give the caregiver time, as well, to focus on his/her relationship with the senior, potentially mending any past unresolved conflicts or enhancing an already close relationship. The following chapter, Spirituality, may help the caregiver, as well as the senior, in their journey together at the end of life.

SUMMARY RECOMMENDATIONS FOR PRACTICE

- Consider the family (as defined by the senior) as the unit of care.
- Observe for, and respond to signs of burden, including emotional distress, fatigue, depression, work-home conflict, and financial difficulties.
- Provide information and assistance with the choice of care settings, whether the home or others.
- Facilitate the family's coming to terms with the impending death.
- Extend support into the period of bereavement.

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chapter 7

SPIRITUALITY

INTRODUCTION

Goals of this Chapter are to:

- define spirituality and religion in relation to end-of-life care to demonstrate how they are both important at the end of life
- explore different methods and rituals which use spirituality to help understand the meaning of life and death

Spirituality means something different for everybody. At the end of life, spirituality can offer meaning and purpose to something which can otherwise defy meaning and purpose. Not only can it help seniors, it can support caregivers - family, professional, and volunteer - to help them better understand the illness and the meaning of suffering. In the context of spirituality, one acknowledges the fear of dying and recognizes the reality of one's physical demise.[1]

Questions arise:

- Who am I?
- Why are we here?
- Is there life after death? If so, what is it like?
- What is the purpose of being on this earth?
- What is the meaning of life?
- How will I spend my next days, weeks, months, years as I continue to age with the increasing possibility of illness, weakness, and dependence on others?
- What gives me pleasure, what makes my heart sing?
- Are the beliefs of my childhood and early adulthood congruent with my beliefs and values of today?
- What is my previous experience of death and dying? How has it affected my sense of my own death or that of a loved one?
- Am I afraid of dying? Am I afraid of being dead?
- Is God a reality?
- When I review my life, do I do so with pride, shame, ambivalence, disappointment, anger, embarrassment, joy, love, justice?
- Who knows my truth? Do I have the courage to speak my truth?
- How do I 'make the most' of the time I have remaining?

DEFINITIONS

Spirituality defies a simple and universal understanding. It may help to think of spirituality as the human capacity to transcend self.[2]

- It is a connection to God or some other power, to a neighbor, to one's inner self and to the environment in the broadest sense.
- All persons experience spiritual needs, whether or not they are part of a formal religious organization.

Spirituality can offer purpose and substance:

- to help find that which is permanent in an ever changing world
- to be able to forgive self and others for wounds and transgressions that may have occurred years ago
- to be able to express anxiety about the life longed for but not lived, and about the features of death that fill a senior with fear
- to find joy in the relationships with family and friends of the past and the present
- to experience satisfaction because of accomplishments
- to feel hope in the sense of a Higher Power

Spiritual and psychological issues at the end of life for seniors with a terminal illness such as cancer, AIDS or Alzheimer Disease can involve a belief in a power greater than the self, commonly termed a Higher Power. What does this Higher Power encompass?

- It has the capacity to love individuals unconditionally and thereby enable individuals to love themselves unconditionally as well.
- Acceptance of oneself and of others results from the love of that Higher Power.
- The Higher Power is able to forgive and to love without judgment or imposition of punishment, and therefore, the individual is also able to forgive self and others for all transgressions imposed on others or experienced personally.
- The strength of this Higher Power enables a senior to experience healing and to resolve personal and relationship concerns; a senior experiences a greater connectedness to others and finds deeper meaning in relationships.[3]

It is important to recognize that not every person, nor every religion recognizes the concept of a "Power". It is important to determine in spending time with individuals as to their perspective on a concept of a source of strength and spirit outside themselves. For some, this is a Higher Power. For others, it may be Buddha, the Creator, Mother Earth, God, Jesus, Nature, Vishnu, Shiva, or another concept.

In the context of a discussion of spirituality, religion must also be considered. It has been defined as:

- a particular system of faith and worship
- human recognition of a superhuman controlling power and especially of a personal God or gods entitled to obedience and worship; effect of such recognition on conduct and mental attitude[4]
- the individual and community values, beliefs, and practices through which persons attempt to fulfill spiritual needs

Religion and spirituality both involve, recognize and value:

- faith in the existence of a spiritual and supernatural power
- faith in the existence of a spiritual dimension of human existence
- a way of interpreting the human experience and bringing meaning and coherence into life
- the human inner potential to transcend past and present circumstances
- the human capacity to know and communicate with God
- the will to meaning as a primary, innate human motivation
- what is sacred, true, and good
- an inner awareness and a subjective experience of the spiritual realm
- encouraging personal encounters with the mystical, supernatural reality
- serving as an inner resource for hope, courage, inspiration, and well-being

- affirmation and celebration of life and human existence
- feelings of self-transcendence, awe and worship[5]

THEORIES OF AGING: ON THE DYNAMICS OF GROWTH AND DECLINE

Spiritual development must be regarded in the context of the development of the 'whole self', in the development of personhood across the life span, on growth rather than decline.

Life span theories can be summarized:

- Successful aging may involve resolving issues relating to integrity versus despair, contributing to the development of the strength of wisdom. Wisdom is a "detached concern with life itself, in the face of death itself. It maintains and learns to convey the integrity of experience, in spite of the decline of bodily and mental functions".[6]
- Resolving these issues can be an important agenda for those who work with and counsel older adults and is important for both psychological and spiritual growth and development.
- Another theory states that the interpersonal relationships that are developed early in childhood[7] can be used to explain the development of values and meaning in terms of spirituality.[8] Reconstructing our meaning schemes about the self and relationships with others including a Higher Power lies at the heart of life review and transformative learning. Learning of this nature can illuminate life goals and life planning.[9]
- The medical model, with respect to seniors, fixes our gaze on the treatment and cure of disease. While it can perpetuate the negative stereotype of aging as characterized by disease, disability and decline, on the other hand, biomedical models of successful aging provide a positive emphasis on physical plasticity and compression of morbidity to old age.[10] The diagnosis and treatment of disease can extend the life span. As well, primary and secondary prevention of chronic disease(s) - such as coronary artery disease(s) - can contribute to compression of morbidity to late life. The implication is that humans cannot only live longer but also live better. Two dilemmas emerge:[11]
  - there is a potential for 'overtreatment'; medical technologies that are effective in prolonging life could have a high cost for the aging individual, in terms of quality of life, and to the health care system
  - a focus on the individual which leads to a lack of emphasis on prevention of social problems that contribute to disease and decline

A humanistic model of health, wellness and self-actualization based on Maslow's hierarchy of needs suggests:[12]

- only when the basic needs - such as air, water, food and shelter - are met does the individual have the motivational energy to negotiate the needs of safety and security in the next level of hierarchy
- pain, suffering and symptoms secondary to disease and aging processes could be seen to comprise the physiological component as well[13]
- essentials of care as found in the biomedical model are necessary in order to address the physiological needs[14]
- the individual ascends through the levels of belonging, self esteem, and growth to the pinnacle of self-actualization, once the these criteria are met[15]

According to Maslow, self-actualization is realized in facing the realities of life and in choosing to be fully one's self, a process through which a person acquires wisdom and maturity.[16]

Our frames of reference and our points of view, which are made up of beliefs, attitudes, opinions, feelings and judgements, affect how we make meaning from experience in order to guide our actions.[17] A process of transformation for individuals and for society as a whole is required in order to develop and promote an integrated and wellness model of aging that incorporates physical, social, psychological and spiritual well being. With respect to working with seniors at the end of life, this process of transformation can begin by actively focusing on positive aspects of aging, seeing the strengths of seniors in how they deal with their situation, focusing on what seniors can do in their present state and appreciating the wisdom they show in their end-of-life stage.

In working with seniors at the end of life, health care and social service providers may be asked to offer advice about spiritual concerns, values or religion. In order to offer this advice, health care and social service providers can use some accepted techniques that have been helpful in other aspects of aging. The following section offers some guidelines in this respect.

LOOKING INWARD: AVENUES TOWARD SPIRITUAL EXPERIENCE FOR SENIORS AT THE END OF LIFE

From the moment of birth, the individual hears and experiences messages from others that inform that person who he/she is expected to be. The individual responds by making every effort to become that person. The original self becomes buried under a mound of voiced and unvoiced expectations. The individual must make choices to become the person he/she is.[18] Asking the question, 'Who am I" can help in this process.

The process of individuation:

- beckons each person to become the true self
- is a quest more than a goal
- is never complete, that is, the self is in constant 'repair'[19]
- may occur at the time of retirement, when the last child leaves home, at a particular birthday, the death of a parent, spouse, sibling or friend, or on learning about a terminal illness
- usually includes a time of self-reflection and the review of a senior's life story

In North American society, ageist attitudes and negative stereotypes, often internalized by seniors, can limit options and choices for meaningful roles. From a developmental perspective, it is possible to hold a positive view of aging where it is appreciated as a time of growth rather than a period of decline. This positive view is focused on psychological and spiritual growth in knowledge, understanding and wisdom, along with the development of self-actualization as one ages.

Psychological and spiritual growth may be enhanced with the aid of a spiritual caregiver. A spiritual caregiver is an individual who in the context of a safe relationship establishes trust such that one is able to explore answers to questions about who we are, our faith or philosophical perspective, our values, our relationship with self, and others including the 'Higher Power'. This person suspends judgment to listen to our story, to mentor, guide and direct as appropriate to a spiritual maturation process. This person may also recommend topics for reading of spiritual writings, instruction on meditation or contemplative silence, encouragement to meet with others who strive to live a spiritual life, to observe nature, and to speak truthfully.[20]

KEEPING A JOURNAL AT THE END OF LIFE

Autobiographical writing can be a valuable tool for those who are terminally-ill, focusing on the experience of the individual and that person's interpretation of events as written by that person. "It is an inside picture of a life as it has been lived".[21] A senior might record daily events, experiences and observations or base the record on themes such as life changing events, relationships with family and friends, work, leisure, among others.

Journaling, as a method of self-reflection, is a valuable tool in assessing a senior's image of aging in the following way:[22]

1. Prepare to write in your journal by sitting in a comfortable chair, closing your eyes, and relaxing your body. Take several deep breaths, emptying your lungs completely after each inhalation. Remain in a meditative state as you become quiet and centered.
2. Ask yourself "How do I feel about aging?" What do I look forward to and what do I fear? Consider these questions in terms of your profession, family life, finances, health, intellectual life, and spirituality. Write naturally without censoring yourself, telling the truth in your own language. Remember that there are no "right" or " wrong" answers in this exercise.
3. Now list negative models of aging that you have internalized from our culture from sources such as literature, films, television, advertising, religious instruction, your family life, and older people you have known. Describe traits and attitudes that may be influencing your own aging process.
4. List positive models of aging that have influenced you. Have you acquired any traits and attitudes that are helping you become an elder?
5. In your mind's eye, make a composite of the good models and imagine what it feels like to walk in the shoes of such a senior. Do you have a useful role in society? Are you earning respect and recognition for your wisdom? Is growing older a blessing or a burden?
6. Visualize going through a routine day as your ideal senior, feeling confident, respected, and socially useful. Be as concrete and detailed as possible in imagining encounters with colleagues at work, loved one, friends and associates, and mentees. Know that by envisioning a positive future, you are seeding consciousness with the expectation of your own potential growth.
7. **Read the Elder Creed:**

   An elder is a person who is still growing, still a learner, still with potential and whose life continues to have within it promise for, and connection to, the future. An elder is still in pursuit of happiness, joy, and pleasure, and her or his birthright to these remains intact. Moreover, an elder is a person who deserves respect and honor and whose work it is to synthesize wisdom from long life experience and formulate this into a legacy for future generations.

Write in your journal any insights or questions that occur to you after reading the Elder Creed. Are you in the process of becoming this kind of senior? What personal and social forces could prevent you from claiming your full stature as an elder?[23]

> *"Reviewing their past helps individuals feel that their lives have had meaning and purpose. Furthermore, it helps them resolve continuing or resurgent conflicts, reconcile internal contradictions, overcome problems, and master complicated feelings or relationships with loved ones. Last, but not least, autobiography becomes a cherished legacy to younger generations".*[24]

LIFE REVIEW

Life review may be common among seniors, in response to the close proximity of death.[25]

The life review process can:

- contribute to integrity and/or despair
- include 'negative' consequences such as anxiety, despair, doubt, anger or depression
- result in 'positive' outcomes including resolution, insight, inner peace and wisdom
- focus on personal integration in terms of the world of work, life projects, life goals and life planning[26]
- contribute to planning the future through reviewing and revising the past in the present
- strengthen and empower people through self-reflection[27]
- enable individuals to co-construct meaning, to collaborate and to develop a stronger sense of community

Life Review Exercise:

1. Down the left side of a large piece of paper, list the seven year cycles of your life:

January, 0-7
February, 8-14
March, 15-21
April, 22-28
May, 29-35
June, 36-42
July, 43-49
August, 50-56
September 57-63
October, 64-70
November, 71-77
December, 78-84 (and beyond).

2. Across the top, divide the remainder of the paper into three sections in which you write answers to the following questions for each of the 12 periods:

a) What were the significant moments and events of each phase of life?
b) Who were the people who guided and influenced you during each period?
c) What did each phase contribute to the continuum of your life?

3. To deepen your memory of people and events, you may want to devote a separate page or more to various time periods. You can enhance your memory by attaching photos to the paper, making sketches, writing little poems that evoke the era, or making a collage of newspaper and magazine clippings. Be creative in calling forth and harvesting the experiences of a lifetime.

4. Use this exercise to help recover memories of experiences that remain incomplete and that you can bring to completion as part of your eldering work. You also can use the exercise for working on forgiveness, recontextualizing difficult outcomes, mining the past for its untold riches, and discovering a future direction for growth.

Exploring what has gone before clears the path for what is to come.

GUIDED AUTOBIOGRAPHY

A guided autobiography which is a semi-structured, topical, group approach to life review[28] includes reflection, writing, themes, metaphors, and verbal sharing. This model combines individual and group experiences with autobiography, incorporating:

- group interaction and leadership to sensitize seniors to the overlooked and unappreciated past and to generate new perspective on the issues of their lives
- private reflection and the writing of two-page life stories on selected life themes
- reading those life stories and sharing thoughts in a mutually encouraging group, moderated by a group leader[29]

There is value in sharing a senior's life story with others. It:

- reinforces and sustains the motivation to review life
- allows individuals to reexperience parts of themselves in the stories of others
- provides a context for the development of new friendships[30]
- may bring to consciousness past experiences, especially unresolved conflicts
- may allow for the older person to find new significance to life[31]
- prepares the senior for death by mitigating fear and anxiety[32]

This process is not dependent on people having a belief that their lives have meaning. It is dependent on a willingness to reflect on their lives as an historical event and may lend itself to finding value in memories, relationships and events. The process of the guided autobiography is such that by asking the questions and thinking about the issues that are raised in each of the themes, the individual will come to know him or herself more fully and may also find meaning, even if that was not believed to be possible prior to embarking on the exercise. It is important for the facilitators to have skills in communication, such as, in listening, suspending judgment, observing non-verbal communication, being empathic, and in creating a safe environment.

Senior persons write and share with the group a series of brief autobiographical life stories based on assigned themes:

- major branching points in life
- family
- career or major life work
- role of money
- health and body image
- loves and hates over his/her lifetime
- sexual identity, sex roles, and sexual experiences
- experiences with death and ideas about dying
- history of aspirations, life goals and the meaning of his/her life[33]

This is generally seen as an important service to:

- older adults, offering an opportunity to develop a greater meaning in life and increased feelings of competency and worth
- those confronted by transitions in life, such as widowhood, retirement, divorce, moving to a nursing home or hospice
- those adapting to a recent disability
- those who must change their lifestyles to maintain health and increase productivity, such as recovering stroke or heart attack victims, and substance abusers
- persons seeking greater understanding and acceptance of themselves[34]

Seniors who participate in life review workshops similar to guided autobiography are better able to adapt their reactions to the possibility of their own deaths and actually increase the reminiscing about their lives after such workshops.[35] This process offers a chance for seniors to:

- reconcile the way a life has been lived and resolve past resentments and negative feelings
- clarify and supply details of the legacy and image he/she wishes to leave behind
- modify plans and choose new activities
- reaffirm the value of the past and derive a feeling of fulfillment in life[36]
- experience a sense of increased personal power and importance
- recognize past adaptive strategies that are relevant to current needs and problems
- feel a resurgence of interest in past activities and hobbies
- develop friendships with other group members
- find a greater sense of meaning in life
- have a greater ability to face the nearing end of life with the feeling that the senior has contributed to the world[37]
- construct their self-identity and provide a sense of satisfaction and fulfillment

It is important for each participant that safety, trust and inclusion be inherent within the process for the group session to be successful. Safety is linked to the sense and degree of control that each participant is given.[38]

MEDITATION/CONTEMPLATION/PRAYER

There are many types of meditation and contemplation within religious traditions. Seniors are encouraged to explore these to discover and learn about those traditions that provide opportunity for a meaningful practice.

Emotions such as fear, apathy, self-pity, anger, and envy may interfere with a senior's willingness to become mindful of his/her inner being. However, in the practice of meditation, a senior becomes aware of his/her experience of life and living, of an openness to that which exists within us. It is a discovery of a senior's self and truth.

> *"As we connect with what we are experiencing in each moment, we begin to discover some things that may have been previously hidden or obscure".*[39]

DREAM WORK

Dreaming is a universal human experience. Dreams:

- give us a great deal of insight into our habits and our nature
- should never be translated into a final meaning, and always given honor and respect, drawing from them as much meaningfulness and imaginative meditation as possible"[40]

DIVERSITY IN RELIGION*†

Edwards (1972) summarizes those features that are common to different religions:

- belief in a supernatural intelligent being or beings
- a worldview interpreting the significance of human life
- belief in experience after death

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* In this discussion, reference is often made to "man". We believe that all religions are for all men, women and children who believe in them. However, as much of the writing on religion refers to "man", we are using this term as the authors have used it.

† Additional information on this topic is in Chapter 8.

- a moral code believed to be sanctioned by a supernatural being
- prayer and ritual, sacred objects and places
- religious experience - awe, mystical experience, revelations

Each of these components affects how people live their lives as individuals and as a society.[41] It is helpful to have a brief knowledge of these components in end-of-life care for seniors of different religious beliefs.

RELIGIONS OF INDIAN ORIGIN

Hinduism

> *Lead me from the unreal to the real. Lead me from darkness to light. Lead me from death to immortality. Brihadaranyaka Upanishad*

Vedic religion was a form of nature worship, in which the powers of nature, especially of the sky, were personified in divinities, worshipped by animal sacrifices.[42] It is taught that there is a supreme or absolute Reality, Brahman, which constitutes the true identity, the Atman, of every being. Spiritual liberation or moksha, bringing release from the endless cycles of birth, death, and rebirth, samsara, is attained through the realization of this identity.[43]

The spirit of Indian philosophy:

- Its chief mark is its concentration on the spiritual - neither man nor universe is looked upon as physical in essence.
- There is a belief in the intimate relationship of philosophy and life, philosophy meaning knowledge of the self or atmavidya.
- Every system seeks the truth as the single entity which serves as a guide for man in his search for salvation.
- Truth must be known; it must be lived. The goal is not to know the ultimate truth but to realize it, to become one with it.
- It is characterized by introspective attitude and the introspective approach to reality. Philosophy is thought of as atmavidya, knowledge of the self. Its focus is on the inner life and self of man rather than the external world of physical nature. That is the most significant clue to his reality.
- Intuition is accepted as the only method through which the ultimate can be known. Reason is insufficient.
- Acceptance of authority is important. Reverence for authority lends itself to a unity of spirit toward the development of philosophical attitudes including spirituality, inwardness, intuition and the strong belief that truth is to be lived and not merely known.
- God is one but men call him by many names.[44]

The Four Ends of Life:

- Moksa: refers to the chief end of man being the development of the individual; to aspire to a universality through his mind and reason, through his heart and love, through his will and power, is the high sense of humanity[45]
- Kama: refers to the emotional being of man, his feelings and desires[46]
- Artha: relates to wealth and material well-being, helping to sustain and enrich life[47]
- Dharma: relates to living one's life for one's own satisfaction, and more importantly, for the community, and most of all for the universal self in each of us[48]

Man becomes completely human only when his sensibility to spirit is awakened. So long as man's life is limited to science and art, technical invention, and social programmes, he is incomplete and not truly human.[49]

Buddhism (Indian)

> *The path to the Deathless is awareness; Unawareness, the path of death. They who are aware do not die; They who are unaware are as dead. Dhammapada*

Buddhis exists in two very different forms: Theravada and Mahayana. **Theravada Buddhism** is based on the Buddha's teaching and is a religion of self-liberation. This teaching is contained especially in:

- the Four Noble Truths
- a statement of the problem: human life is pervaded by suffering
- the belief that suffering is caused by excessive attachment to our ego. However, Self-centered desire can be extinguished, and with that, suffering. The remedy is to abandon the Self. We can do this by following the Eightfold Path:
    - Right Understanding: Comprehend the first three Noble Truths
    - Right Thought: Foster thoughts of non-violence and love
    - Right Speech: Avoid speech which causes harm
    - Right Conduct: Practise behaviour which causes no harm; one should do what is possible to help others
    - Right Livelihood: Avoid ways of earning a living which may result in harming others e.g., dealing in arms, selling intoxicating drinks
    - Right Effort: Determine and make the effort to eliminate and prevent bad states of mind. Cultivate good and wholesome states of mind
    - Right Mindfulness: Become aware of one's self, bring the unconscious into consciousness
    - Right Concentration: Practice deep meditation, thereby attaining peace of mind, and the Ten Precepts:
        - Not to destroy life
        - Not to steal
        - Not to commit adultery
        - Not to tell lies
        - Not to take intoxicants
        - Not to eat at forbidden times (i.e., after midday)
        - Not to dance, sing, play music, or act on the stage
        - Not to use perfumes or jewelry
        - Not to use a high or broad bed
        - Not to receive gold or silver[50]

Mahayana Buddhism is based on the Buddha's example, his actions. The Buddha is the embodiment of infinite compassion.

- The compassion of the Buddha is symbolized in the concept of the Bodhisattva, who renounces Nirvana in order to help others, and by that fact enters it.
- Mahayana Buddhism exists in two different but related forms, the meditational and the devotional.
- Meditational Mahayana emphasizes that we are already saved, and only need to realize that fact.
- Devotional Mahayana seeks the aid of the Buddhas and Bodhisattvas in achieving salvation and in overcoming the trials of this life.[51]

Buddhism (Chinese)

- It is a synthesis of elements from Indian Buddhism and Taoism.
- Meditational Buddhism seeks the Buddha in one's own heart.

- It is characterized by the concreteness, spontaneity, love of paradox, and aversion to theory of Taoism.
- Devotional Buddhism seeks rebirth in the Pure Land of the Buddha A Mi T'o.[52]

RELIGIONS OF SEMITIC ORIGIN

Judaism, Islam, and Christianity share several fundamental conceptions:

- God (monotheism)
    - single divine Being
    - personal
    - eternal
    - all-powerful
    - all-knowing
    - all-good

- Creation
    - God creates a world which is distinct from himself
    - real, not illusory
    - totally dependent on God
    - good

- Revelation
    - in a unique historical event
    - God reveals his will, requiring obedience, disobedience being sin
    - given in writing

- Immortality and Judgment
    - life after death
    - God will judge each individual, for reward or punishment

These religions emphasize the significance of:

- persons as superior to nature
- the individual human person, who must answer for his/her thoughts and deeds
- the moral value of justice
- law
- history, which moves not in an everlasting cycle, but in a straight line, from a beginning to an end

Hebrew Religion

- ethical monotheism
- God makes a covenant with the Hebrew people
- requires observance of his Law, the Torah
- focuses especially on the temple and ritual sacrifice and justice[53]

Judaism

- continues the Israelite conception of God
- it transforms the conception of the Law to make allowance for the changed political circumstances following the

destruction of the temple in A.D. 70

- elimination of the ritual sacrifices
- the synagogue system and rabbinate replace the temple and priesthood
- its immediate basis is the Talmud rather than the Bible
- enlargement of the concept of Torah to include the Talmud
- a religion of the individual and the family, and of everyday life, expressed in Holy Days, rites of passage, dietary laws, and the use of symbols in prayer[54]

Islam

> *In the Name of God, the Merciful, the Compassionate...Thee only we serve; to Thee alone we pray for succour. Guide us in the straight path....Qur'an 1:5*

The chief message of the Koran is the absolute supremacy of God. The main doctrines of Islam are:

- the existence of a single God
- angels
- prophets and scriptures
- resurrection and the Last Judgment
- the Divine Decree and predestination

The principal duties incumbent on a Moslem are the Five Pillars of Islam:

- recital of the Shahada (confession of faith)
- formal prayer, Salat. (worship)
- legal almsgiving, Zakat. (wealth sharing)
- fasting, Sawm.
- pilgrimage to Mecca, Hajj

Islam is not only a private or individual religion, but a social one.[55]

Christianity

> *In the Cross is salvation, in the Cross is life...Take up therefore thy Cross and follow Jesus: and thou shalt enter into life eternal. Thomas a Kempis*

According to the New Testament Gospels, Jesus preached that:

- the Jewish Law was fully kept by loving God and one's fellow man
- Jesus' teachings inaugurate the kingdom of God on earth, the invisible realm where God's will is obeyed
- to enter it, men must repent of their sins and forgive others their offenses
- after death there is a judgment, and there will be a resurrection of the dead
- Jesus will return, bringing the present era to an end, and making the kingdom of God visible and triumphant

The apostle Paul, whose letters to the early Christian communities are contained in the New Testament, preached that:

- the human race is sinful, having inherited sin from Adam, and so all men are condemned in God's sight
- Jesus has saved mankind form sin and restored man's relationship to God through his death and resurrection
- to become a Christian is to participate in Jesus' death, resurrection, and eternal life. Through faith in Christ we share in his life, which overcomes both the spiritual death of sin, and also the physical death of the body[56]

Clearly, there are both many similarities as well as differences among the many faiths. It is important that the seniors' beliefs are respected by all those involved in end-of-life care.

FUNERALS/MEMORIAL SERVICES: KEY CONSIDERATIONS*

> *"Death rituals are viewed as rights of passage. As such, they provide formal recognition of the transition from one stage in the life cycle to another and the changed status that transition brings. Death ceremonies help to psychologically remove the deceased from this earthly existence to the symbolic world of the dead. Likewise, they publicly mark the changed status of survivors, reuniting them in their new role in society".*[57]

DEFINITIONS

Funeral: burial [cremation] of the dead with its ceremonies, obsequies; burial service or procession[58]

A funeral includes a process of committing the body to natural processes of physical degeneration (often the body is present in a casket or, if cremated, in an urn), remembering the person, and acknowledging, for some, a spirit or spiritual dimension to the individual. The memorial services generally exclude the presence of the body or the process of burial or cremation. The deceased may be represented by a picture.

Memorial: serving to commemorate; of memory[59]

Funerals:

- increase the reality of death
- provide a legitimate public occasion for expressing and validating grief
- provide evidence for the worth of the senior who has died
- provide social support for the survivors
- can help occupy the bereaved person's time in a difficult situation
- provide predictability and organization in the midst of an uncontrollable situation
- present an opportunity to reflect on our own mortality
- may reaffirm ethnic or religious identity
- emphasize the cohesiveness of the family or larger group beyond the loss of one of its members
- remind survivors that structure, organization and life go on
- reaffirm social order
- help children to learn about death and about the comfort, love, and support that humans can provide each other in times of crisis
- mirror the values and expectations of a society
- provide an opportunity to examine the nature of life within a cultural group[60]

The funeral provides the opportunity for the survivors to contemplate the meaning of life and death, to celebrate the life and personhood of the senior who has died, to formally bid farewell to the senior, to grieve with others and to begin the process of integrating the loss and absence of a loved one into the lives of those who continue on with living.

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* Additional information on this topic is in Chapter 9.

Significant features of funerals and memorial services are the people who speak, how they speak and what they say. Readings, music, the eulogy and rituals are vital to the process of acknowledging the individual who has died, the grief of those who live, and the recognition that healing is a complex process which requires varying degrees of time.

Aspects of mourning:

1. **Acknowledge the reality of the death**. This usually happens in two phases:
   - in our minds. Funerals and memorial services serve to teach us, the people who attend the service, that someone we love has died.
   - in our hearts. It is at this time that people are invited to confront the disbelief that the person one has loved is gone and cannot return.

It is essential to respect the cultural and religious differences within this context. The funeral/memorial service may serve as the threshold of the doorway to healing.

2. **Move toward the pain of the loss**. For some, this service is the only legitimate place condoned by society for openly outward expressions of sadness.
3. **Remember the person who died**. This service provides a natural opportunity to speak, think and feel about moments of memory - good, bad, pleasant, painful, collegial, intimate - about times shared with the person who has died.
4. **Develop a new self-identity**. The death of a family member or a friend marks a change in one's role(s) and the beginning of a new and different identity. In the depths of one's grief-filled response to the death of someone close to us, it is important to have others around to help us realize the severity of our grief and the reality of our importance and existence to them.
5. **Search for meaning**. The natural outcome of the death of someone close to us is to question the meaning of life and death, of existence as we know it, of the possibility of life after death.
6. **Receive ongoing support from others**. Funeral/memorial services are a strong statement that no one is alone in their grief. Connections are made to other family members and friends who will continue as such through the process of healing and may be very important to the process.

BURIAL: KEY CONSIDERATIONS

The way in which humans dispose of their deceased persons varies according to culture, religion, personal preference, and even geographic area. This usually includes burial, entombment and cremation.

Most people in North America are buried in the earth after their death. While grave space is diminishing in urban centres, methods of cremation and entombment are increasing in popularity.

Entombment occurs in a mausoleum. In this method, the casket is placed in a building, known as a mausoleum, above ground, arranged in rows stacked one above the other. These buildings are usually located on cemetery grounds.

Cremation uses intense heat to reduce the body to bone ashes and may be stored in structures, known as columbariums, buried, or scattered.[61]

CONCLUSION

The crisis of life-threatening illness and loss is found on a variety of levels. There are medical and physical crises as well as psychological and social ones. But there are also spiritual crises as a senior struggles to find the meaning in the midst of disease, death, and loss. At each phase of the illness or subsequent loss, the ill person, as well as his/her family, may confront different issues. But in each case, the question is essentially the same: "What can this possibly mean?"[62]

Our spiritual and philosophical systems of beliefs and thought provide the building blocks for the quest to find or understand meaning and purpose. It is this underlying spirituality that allows seniors with illness, and their family and friends, explanations or understandings of crisis as well as concepts such as forgiveness, value, altruism, love and sacrifice that can help surmount the crisis.[63]

In the end, the quest for meaning in life-threatening illness and subsequent loss is critical. Some seniors will have their concerns strengthened and reaffirmed. Others may be unable to find meaning, leading to an enduring sense of despair. Such a result reminds us that an underdeveloped sense of spirituality can be crippling as we struggle with life-threatening illness. Not to have pondered life's mysteries, at least on some level, leaves one ill-prepared to confront death. But still, to others it is a transformative event that offers individuals new meaning for understanding life, illnesses and death. These rediscovered or reconstituted meanings can allow seniors, even in the midst of a devastating crisis and an alarming awareness of personal mortality, to experience new insights, to find renewed strengths, and to achieve personal growth.[64]

SUMMARY RECOMMENDATIONS FOR PRACTICE

- Recognize the importance of spirituality in the lives of seniors.
- Encourage the use of strategies such as keeping a journal, life review, guided autobiography, meditation, contemplation and prayer, and dream work that support the finding of meaning in adversity.
- Recognize the diversity of religions and understand their underlying assumptions about death and dying.
- Respect religious rituals and ceremonies that surround death and dying.

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chapter 8

THE CULTURAL CONTEXT FOR PALLIATIVE AND END-OF-LIFE CARE FOR SENIORS

INTRODUCTION

Goals of this Chapter are to:

- foster an atmosphere where the expression of culture is encouraged and celebrated
- prevent the occurrence of events that will distress patient and family
- help ensure optimal person-centred care and caring
- develop end-of-life care that is culturally sensitive by culturing awareness through the health care and social service provider, the health care team and the health care organization, program or institution

Significant life passages are heavily influenced by culture. Dying is a significant life passage, like birth, entry into adulthood and marriage, and as such, the approach of death and the time around dying are life events where cultural values and practices will be important for all involved. Culturally appropriate care must then be provided by staff members who are culturally sensitive. The focus and positive benefits of this approach to care are threefold:

- to foster an atmosphere where the expression of culture is encouraged and celebrated
- to prevent the occurrence of events that will distress the senior and his/her family
- to help ensure optimal person-centered care and caring

This celebration of culture provides for the mutual enhancement of patient and family and health care and social service providers. The importance of developing a culturally aware practice is emphasized by statistics which illustrate the cultural diversity of older Canadians. For example, 68 distinct cultural backgrounds are cited by Canadians age 65+ when asked their ethnic origin.[1]

No doubt we are experiencing cross-cultural exchanges all the time. A heightened awareness and interest will enrich this experience for all involved.

> *"Culture, ethnicity and religion weave the fabric of each person's particular response to treatment and healing".*[2]

This is most certainly true for serious illness that may result in death among seniors. Influences from these origins, the significant influences of family, friends and social circles, and the larger surrounding society and culture, past and present, help develop the belief system of seniors and, in essence, make them who they are.

The uniqueness of each person is created and manifested through the way these weave together and for the particular importance that they give to various aspects of these influences.

DEFINITIONS

It is helpful to have a working understanding of these three different but closely related concepts.

Culture:

- "the learned, shared and transmitted values, beliefs, norms and lifeway practices of a particular group that guides thinking, decisions and actions in patterned ways"[3]
- "the sum total of socially inherited characteristics of a human group that comprises everything which one generation can tell, convey or hand down to the next; in other words, the non-physically inherited traits we possess"[4]

Ethnicity:

- a social group within a cultural and social system, that shares complex traits of religious, linguistic, ancestral or physical characteristics[5]

Religion:

- "the belief in a divine or superhuman power or powers to be obeyed and worshipped as the creator(s) and ruler(s) of the universe
- a system of beliefs, practices, and ethical values"[6]

The influence of culture, ethnicity and religion will vary for seniors over the course of their life journey. They may be influenced by changes in their present surrounding culture, their educational experiences, the people they have met and married, people in their social circle, and their own life cycle stage.

- Seniors, for example, may physically have moved from their culture of origin to another culture. In later life, they may find themselves returning to previous cultural and religious practices in a way that more closely resembles their own earlier pattern or that of their parents.

Serious illness, with its threat of death, is a powerful stimulus for all seniors to review their life, and to seek meaning in their life journey, past experiences, cultural traditions and religious beliefs and practices.

One of the cornerstones of cross-cultural care and practice is the importance of considering each senior as a UNIQUE INDIVIDUAL. We are, to some degree, products of our culture, and are influenced by it in an on-going way. However, it is important to treat all seniors uniquely, not as a member of a cultural group who is expected to believe certain things and behave in a certain way. It is important to remember that everyone has a cultural heritage.

- Even systems for care delivery (hospitals, long-term care facilities and home care programs) and the people who work in them have a culture that might be referred to as the "culture of health care and social service providers". Such a culture has its own values, ways of being, ways of speaking and relating and even its own language and terminology that make it distinct. Seniors entering the system for care and thus, the "health care and social service provider culture", will be entering a new "culture" with which they may be unaware and possibly unfamiliar. We need to be sensitive to this fact.

PHILOSOPHY OF PALLIATIVE CARE: CULTURAL INFLUENCE

The philosophy of palliative care is based upon the belief that individuals are unique persons, to be valued in and of themselves until the time they die. Dying people are regarded as partners in their health care and their needs and wishes must be respected.[7] The original concept of palliative and hospice care was developed in the United Kingdom in the early 1960's. Its roots were Anglo-Saxon and, to a great extent, based upon Judeo-Christian beliefs and values. Since that time, both the philosophy and practice of Palliative/hospice care have spread widely and are now being adapted in other countries, cultures and socio-economic situations.

- In a cultural context, what does it mean to be a senior, ill, frail and dying? What does it mean to the senior's family?
- Death and dying represent a life crisis for the senior and family members; it is also a situation of major loss.
- For seniors who have immigrated to Canada, this may be yet one more of many significant losses they may have experienced in leaving their homeland. In times of severe distress, seniors may turn to past cultural practices as a source of comfort and perhaps protection.

Certain important components of palliative end-of-life philosophy and practice may be influenced by culture in terms of beliefs, expectations and familiarity. These include:

- the concept of the senior and family as the unit of care
- physical aspects of care, including symptom control
- psychosocial assessment and support
- ethical dimensions of care and the underlying values
- decision-making and setting goals of care
- processes of caregiving in terms of involvement
- expressions of grief and rituals of mourning

HOW MIGHT A SENIOR'S CULTURAL HERITAGE UNIQUELY INFLUENCE END-OF-LIFE CARE PRACTICE?

There are several aspects of end-of-life care where personal beliefs and cultural influences may have impact. It is important to be aware of these beliefs and influences because the process of dying is, in many ways, a private event and one that must be carried out, as much as possible, in a way that the senior wishes.

PHYSICAL CARE

The Values and Beliefs that Surround Pain and Pain Control*

Culture can influence:

- the acceptability of expression of physical pain
- the manner of expressing that pain is being felt
- the meaning that may surround the presence of physical pain

For example, some cultures may value a stoic demeanor when in pain, while others will encourage overt expression of pain and distress. Neither way is "better" than the other. Rather, they are each unique. This variability may present unique challenges in assessment and treatment of pain, in order to avoid under treatment and partial relief. Careful observation, knowledge of the disease (is it one that is likely to be pain-producing?), as well as reported pain

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* Additional information on this topic is in Chapters 4 and 7.

and pain relief will be essential to good care. As well, cultures may have differing views about the role of suffering and its relation to physical pain and the way suffering is expressed. The degree to which pain and suffering can be relieved and by what means will also be affected.

Opioid Analgesics

Many cultures, including the North American culture, have biases, misunderstandings and fears about opioid analgesics like morphine. Concerns include:

- whether they can be taken for pain relief
- the way the senior who takes them will be viewed
- which side effects may be attributed to the drugs
- whether seniors will be able to comply with plans for care
- the fear that the analgesics may be "mind-altering" (the senior will not be him/herself)
- moral judgments about opioids
- unnecessary fears about addiction

Most seniors of all cultures require reassurance and education about the safety of opioid analgesics in the palliative setting. These fears and misunderstandings may be more prevalent in the family of the sick person than the senior him/herself. Anxiety about the use of these medications may be more prevalent within some cultures than others and religious beliefs may play a part. Religious leaders can play an important part in allaying anxieties and fears, particularly when they are included in the health care team.

Physical Touch

It is important to determine the role of physical touch within a culture. Some considerations:

- Who may touch whom? And in what context (e.g., for physical examination and tests, bathing and other care)? In some Eastern cultures, men may not touch women. This may have implications for the female team member who, on introductions, offers her hand to a male.
- Some cultures and societies use certain hands for certain personal functions and for touch. For example, in Arabic cultures, the left hand is used for toileting and the right for giving and taking food and other interactions of touch.
- In some societies, men and women may not touch.
- Can touch be used in the process of providing emotional comfort and by whom?
- Perhaps certain family members must be present during physical examination when touch is a part of the process. For example, an older female patient may be more comfortable with her daughter or her husband present. The team will need to ask about these matters.

Privacy

Physical privacy may be very important to seniors in certain cultures.

- For example, the practice of veiling the face is essential for women from certain Middle Eastern societies. The presence of drawn curtains around the bed may be necessary and desirable for others.

Physical Care Set-arrangements

There may be needs for particular physical arrangements.

- Seniors who are followers of Islam, for example, will require that they face the East (Mecca) in times of serious illness and as death draws near. To accommodate this belief, the senior's bed may need to be moved or his/her face could be turned to the right as a symbol of this belief. Also, prayer times and the attendant ritual bathing will require some accommodation on the part of hospitals and long-term care settings.

Dietary and Nutrition Requirements

Food and eating are powerful symbols in all cultures. They play central roles in ceremonies and social events and they represent nurturing and love. It is, therefore, not surprising that all matters related to food and eating will be affected by matters of culture. Food also plays a vital part in survival. Therefore, a palliative patient's inability to eat will evoke powerful and distressing emotions in them and their family members. Sensitive understanding about the social and cultural meaning of food and eating will facilitate support for the senior and his/her family.

Some cultures and religions have dietary requirements and preferences which may include:

- the types of food which may and may not be eaten
- who may handle, prepare and serve food and in what types of containers and dishes
- the meaning of food, of eating, and of practice around meals

For example, the Jewish faith and culture, Seventh Day Adventist Faith and the Islamic faith each have dietary requirements. As always in cross-cultural care, it is important to approach each individual senior as a unique person in these matters, because the role of dietary practices will vary. Every effort should be made to facilitate what is required. Families are often most eager to participate by giving information and bringing food into the care setting. Nutrition professionals can assist in modifying medical nutrition needs using the foods of a particular culture.

Personal Care Practices

Seniors may have particular cultural habits around such functions as toileting and bathing. As much as is possible, the means should be provided for them to provide their own care in a way comfortable for them. Areas of concern:

- Seniors may be unfamiliar with such items as bedpans and commodes and may need sensitive explanations.
- As mentioned, seniors from some cultural groups, for example, Middle Eastern cultures, use only the left hand for toileting. It may be distressing for older individuals if intravenous and other lines prevent this.
- Seniors from some cultural groups have personal cleanliness habits that are extremely important and must be respected and facilitated, wherever possible, by health care and social service providers. Family members will be most helpful in assisting. For example, for followers of Islam, ritual bathing may be required prior to prayers.

Complementary and Alternative Therapies

Complementary or alternative therapies are unproven methods or activities used to cure or treat diagnosed diseases. They lack scientific or clinical evidence of effectiveness in peer-reviewed literature. Their use is widespread in all cultures. Some of the medicines ingested or applied to the skin are chemically active in the body, particularly if they are derived from plants or herbs.

Many seniors of all cultures, including the North American culture, use complementary therapies of a variety of types:

- in the form of physical therapies
    - in the form of preparations that are ingested, applied or given as enemas
    - in the form of massage and physical treatments
- in the form of emotional/spiritual therapies such as rituals, prayers, chants and other practices

Health care teams should assume that complementary therapies are being used and inquire about them as a part of routine patient and family assessment. Some seniors may use these while participating in recommended medical treatment programs and others will use these as alternatives, forsaking recommended medical care. It is important to know the complementary/alternative therapies seniors may be practicing not only to be aware of potential adverse drug interactions, but also to support those practices that may have great meaning for the senior and his/her family. It can be quite interesting and challenging to seek information about complementary therapies, for example, Chinese medicine. Cultural communities, traditional healers, alternative practitioners, and pharmacists may be some of the resource people who can assist.

COMMUNICATION

Communication in any society is a complex phenomenon, interweaving verbal and nonverbal processes. It involves who we are as people (our way of being), what we say, how we say it, as well as the many gestures and other body language messages that we consciously and unconsciously send. Within many cultures, communication is complex, both powerful and subtle at the same time. There are certain aspects of communication in palliative and end-of-life care which will be culturally influenced.

TRUTH-TELLING ABOUT DIAGNOSIS AND PROGNOSIS OF AN ILLNESS

Variability in the cultural value placed upon truth-telling about serious and incurable illness can be one of the most problematic areas of cross-cultural care for health care teams. In Western cultures, it has become the norm in health care practice to place a high value on autonomy and on the sharing of truth about the nature of an illness and its likely prognosis. However, variability may exist.

- Some seniors and their families from different cultures, or even within North American and Western cultures, may take quite a different view, believing that the truth about the illness should be kept from the senior as it would only serve to upset the individual and cause him/her to lose hope.
    - To what degree are views about truth-telling related to a particular culture or to the viewpoint and beliefs of a particular senior or family? It will be important to explore this on an individual basis. The health care team cannot assume that everyone within a particular culture will approach this matter in the same way. For example, people from eastern Europe or from Italy, Spain and Portugal may not share the nature of serious illness with their ill family member, and may request that the senior not be told. However, individuals and families within these cultural groups may wish a more open dialogue about illness and prognosis.
- The inability to tell a senior the nature of his/her situation has great impact on the whole process of ethical decision-making, treatment decisions and planning for care. It can also affect the way that emotional and spiritual support can be provided to the sick person.
- Family members are usually the ones who request that their loved one not be told about the illness and prognosis. Their reasons for this are a belief that not telling will protect their loved one from emotional pain and despair. They may request this whether there is a language barrier with the senior or not. Health care teams can help families understand that their loved one likely knows that they are seriously ill and that they may find it lonely and isolating not to be able to talk with family about the illness and future.

Truth-telling may be a universal human value rather than being culturally specific.[8] However, at the level of individual patient care practice, it can be difficult and may even be inappropriate to transcend family and cultural wishes in the matter of truth-telling. Health care teams become very distressed in this situation where truth cannot be told, because they feel that they are somehow deceiving the senior. This is a reflection of the very high value North American culture places on truth-telling.

- It can be helpful to try to determine what the senior might expect to have happen if he/she was seriously ill.
- It can also be helpful to determine what sense the senior might have about how seriously ill he/she is, even if he/she cannot be told the specifics.

Lack of a Common Language

One of the greatest obstacles to effective communication is lack of a shared language. Sometimes, the senior and family may know some words in the language of the health care and social service provider. The importance of taking time, using simple words, and non-verbal communication become very important in this situation. Access the services of an interpreter if available.

The Role of Talking and Sharing Emotions

Western societies tend to place a high value on "talking things through" and also on the sharing of emotions in times of distress. This is not necessarily the case with other cultures. Health care and social service providers may feel puzzled and somewhat helpless as to how to assist seniors who are not able to express how they feel or who do not feel comfortable talking about their situation. It can be difficult to determine how to provide on-going support. Non-verbal ways of communicating support may be very important in these situations.

Non-Verbal Ways of Communicating

There are many non-verbal ways of communicating kindness, empathy, respect and understanding:

- sitting quietly at a bedside with a senior
- sharing tea with a family circle
- being aware of respectful body postures, gestures and facial expressions
    - a pleasant demeanor, smile, a touch of support on the hand or forearm

A picture truly is "worth a thousand words" and the way we look and behave when interacting with seniors and families can convey volumes of respect, support and caring when we do not have a shared verbal language.

Some aspects of non-verbal communication are particular to cultures:

- Direct eye contact is valued in Western cultures as a symbol of openness and personal strength of character while, in other cultures (i.e., Aboriginal cultures), direct eye contact may be interpreted as rude or disrespectful.
- For North Americans, the "personal space" comfort zone when talking or interacting with someone is about 18 inches to two feet, while in Middle Eastern and Latin cultures, this space may be shorter and people will stand closer when interacting. Such subtle and unique customs can be misinterpreted if their basis is not understood.

ETHICAL DECISION-MAKING*

When a senior is dying, it is necessary to make decisions about the goals of his/her care, the general approach to treatment that will be taken and, particularly, whether life-prolonging treatments will be utilized in care. Such life-prolonging treatments include use of intravenous fluids, artificial feeding, antibiotics, transfusion, artificial ventilation, palliative radiation therapy or chemotherapy and other modalities among others.

- In North America, it is the custom to discuss such matters with the senior and family, thus honouring patient autonomy and informed consent and enhancing a collaborative decision-making approach to care. This practice forms part of the ethical basis for care at the end of life.[9]

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* Additional information on this topic is in Chapter 4.

- People from other cultures may find this approach confusing and perhaps frightening, because they would expect health care and social service providers to know what is the best way of treating the senior and to go ahead and do this without consulting family members. Individual autonomy may not be an integral part of certain cultures. The family system and the common good of all may be as valued as the good of the individual him/herself.

Besides differences about individual autonomy, truth-telling, informed consent and joint decision-making, the other areas of ethical decision-making which may prove challenging from a cultural viewpoint relate to artificial feeding and hydration, and the question of how far to go in prolonging life. Cessation of treatment and non-initiation of treatment for seniors may not be acceptable practices in some cultures on the basis of cultural and religious beliefs. Matters of artificial feeding and hydration may be particularly influenced by culture practices and religious beliefs.

ROLE OF FAMILY AND FRIENDS

The role of family will vary with culture. The family system is unique in terms of:

- the roles of family members
- lines of authority
- gender roles
- who makes decisions
- who can come to and participate in family meetings
    - For example, while western cultural tradition might see the wife of the senior as a key player in decision-making and family meetings, in some cultures, she may not have such a significant role in decision-making. In many cultures, the eldest son or sons may make treatment decisions for older parents. It may be difficult to separate the wishes and needs of family from those of the senior, because, in many cases, the family will be speaking for the senior and interpreting the culture to the health care and social service providers.

The family may wish to be present with the senior at all times. Cultural expectations may dictate that family remain with the older patient continuously, thereby demonstrating that the more people with the senior, the greater the evidence of respect and love shown. It may be a sign of disrespect not to visit when someone is dying Thus, large numbers of people may wish and need to be with the senior in the dying phase of illness, the time of death itself and the bereavement period. The body of the deceased person may not be able to be left alone and prayers may be said continuously in the presence of the deceased.

EXPECTATIONS OF HOSPITALS, CARING INSTITUTIONS AND HEALTH CARE AND SOCIAL SERVICE PROVIDERS

Various cultures will see the roles of health care and social service providers and institutions from a unique perspective:

- Explanation may be required to help seniors and their families understand the role of the nurse and other team members, how the hospital routine works and other matters.
- The changing role of hospitals (i.e., early discharge home or to long-term care facilities) may not match cultural expectations in the sense that people may not understand why their loved one cannot stay in the hospital when he/she is clearly sick and dying. Many cultures view hospitals as the place where one can stay when very ill and dying. Other cultures may want to take their dying family member home when they are going to die.

- Some cultures do not see long-term care settings as an acceptable option but, at the same time, may not be able to assume the burden of care at home, even with maximal home care supports. Some people may not understand why home care cannot include a nurse 24 hours a day.
- Other families will want to be with their sick older family members around the clock, even if there is not an illness crisis. They may not understand the concept of visiting hours in a four-bed hospital room.

Such differing viewpoints require subtle negotiation and explanation on the part of health care and social service providers, as well as flexibility on the part of the health team, hospital, and the senior and family. Usually, a middle ground can be found where everyone can feel comfortable.

RITUALS AND CEREMONIES

Because death is a significant life passage, it may be accompanied by rituals and ceremonial practices. Death and bereavement mark some of the most elaborate and well-defined rituals that are seen in cultures throughout the world. Some rituals:

- provide intervention for the protection and safe-passage of the soul at the time of death and to the next world
- demonstrate grief and loss
- involve chanting, wailing (or ululation), praying, burning of incense, positioning of the sick person and his/her body after death.

These rituals are essential and therefore must be permitted. It is helpful to know what might occur so that privacy can be provided, staff can be prepared, and other patients and families reassured. It is also essential for health care and social service providers to know what is required in terms of the body at the time of death and thereafter:

- Can the deceased be touched, bathed and prepared by staff?
- Can the person's body be moved?
- How soon must the person be buried or cremated?
- Is the body transferred to the morgue or otherwise?

GRIEF AND MOURNING

Grief and mourning are heavily influenced by culture. Culture can assist and support the family and friends of the senior who has died by providing customs and guidelines for:

- the manner of grieving
- the behaviour of the bereaved people
- what is appropriate for visitors
- what people wear
- what to eat and drink
- what visitors may bring to the bereaved people

Such detail can be helpful to everyone in a time of distress as the rituals provide a comforting supportive structure for mourners and all people involved.

Many rituals also surround the burial and bereavement period. The purpose of such rituals may be to allow family and friends to express the loss of the deceased person and to provide a means whereby others in the community can provide comfort and support to the bereaved.

Health care teams will need to know particular ways that grief will be shown when caring for a particular senior and their family and community. For example, the degree of overt emotion likely to be shown at the time of death will vary from culture to culture. People from Anglo-Saxon and aboriginal cultures may not show overt signs of grief, while people of Greek, Latin or Eastern cultures may appear very distraught and perhaps faint or feel physically weak. Knowing this before the time of death, the health care team can be prepared to support the family in the manner most helpful to them.

Jewish people will sit Shiva for seven days following death and will receive friends at home at certain times. Some women of Italian, Spanish or Portuguese cultures will wear black for one year after death, or for the remainder of their lives. Again, it is best to inquire of the individuals involved what practices will be followed.

CARE AT HOME

Care in the home will provide the most intimate view of the cultural dimensions of end-of-life care. It is a very great privilege to enter someone's home for the purposes of providing health care. It can be helpful for health care and social service providers to view themselves as guests in the home. The "ritual" of a home visit requires much interpretation on both sides - that of family and that of health care and social service providers. This ritual may incorporate an understanding of:

- what the cultural views of time may be. For example, there may be varying interpretations of "on time" and of time frames and expectations within those time frames.
- entry into the home (are shoes removed, for example?)
- procedures of obtaining information
- explanation of health care roles. Some cultures may be somewhat uncomfortable with persons in their home who are not of their culture. It is important to clarify roles and expectations and tread sensitively and respectfully.
- carrying out the personal care
- refreshments which may be offered at the end of the visit. It may be part of the caring relationship to accept these.

SPIRITUALITY, FAITH AND RELIGION

As indicated earlier, religion and culture are often so closely related that it can be difficult to tell from which source certain practices might arise:

- North American culture bases many of its values, legal systems and ethical practices in the Judeo-Christian religions
- The Islamic Faith is intimately woven into the cultures of some countries of the Middle East.

In both examples, people may not be completely aware whether a particular belief or practice is based on culture, religion or both. Also, it is important to be aware that seniors living in a particular country may or may not be of the same faith although they share a culture and cultural heritage. For example, people from India may be Hindu, Christian or Muslim. People born in Canada may hold one of many faiths although they share a common Canadian cultural heritage.

There may be intergenerational issues in terms of the degree of adherence to culture and religion. For example, the older members of a family may hold more traditional views than those of their adult children and grandchildren. Religious leaders may be important team members in meeting the palliative care needs of seniors. They may be a source of support and comfort for the sick person and family. They can also be a source of information and support to the health care team by assisting in providing information about the culture and religion which will help in the provision of care. It is very important to take the lead from family members and the sick person about the role that faith and religion play in their lives and the role they would like religious leaders to play in their care.

BELIEFS ABOUT CAUSATION OF ILLNESS

People of various cultures may have particular views as to the cause of the illness in their loved one. These beliefs (i.e., seeing the illness as an incurable one) may influence care in a number of ways including the complementary treatments they may employ and their ability to make treatment decisions (i.e., stopping life-prolonging treatments even though health care and social service providers have explained that these are not of benefit to the older patient).

- For example, if the illness is thought to have been caused by a misdeed of the senior, family and patient may believe that a means can be found to restore the senior to a place of honour and thereby, cure the sickness.

WHEN A SENIOR IS A REFUGEE

As well as exploring aspects of culture, it is important to explore to some degree the circumstances under which the senior left his/her country of origin to come to Canada. Elective choice to immigrate to a new country is not the same as needing to flee to a safer place. Also, some people may have been living in fear prior to immigration, they may have lost family members to war or political persecution and they themselves may have been tortured. Some knowledge and appreciation of these facts can provide a further understanding of the burden of suffering of the sick person and his/her family.

- Family members or religious and cultural leaders can be very helpful in providing this type of background information.
- If the ill senior understands English, he/she may wish to tell his/her story.
- It is equally important to remember that some of this background may be very painful to recall and the ill person and family may wish not to talk about it.
- A history of fear, loss of loved ones, emotional suffering, physical injury and particularly torture may add unique complexities to the pain of physical illness and impending death. This may impact pain management, perhaps augmenting the meaning of the pain and the aspect of psychospiritual suffering that attends it; intensive support will be required.

DEVELOPING CULTURALLY AWARE END-OF-LIFE CARE PRACTICE

Fostering a culturally-aware practice must occur on three levels, that of

- the individual health care and social service provider (oneself)
- the health care team
- the health care organization, program or institution

ONESELF

The mindset of practicing in a cultural context begins with self-reflection. A few approaches will help in this process:

- Sincere interest, a desire to learn and curiosity about other ways of being and living is a prerequisite.
- Heightened awareness and sensitivity to the cultural aspects of life generally and of illness and dying specifically can be learned.
- Examination and reflection about one's own culture and its influence on oneself can be illuminating.
    - What is my background, how might it have influenced my values, beliefs and ways of being and living?
    - How might my own culture influence the way I feel about illness, death and loss and how I express my feelings and thoughts about these important life passages?
- Open reflection about one's own cultural biases is paramount to understanding one's feelings and behaviours, gaining insight, and beginning to move forward to a bias-free way of relating to other people. Such reflection is also important in one's own personal growth.
    - How do I feel about certain people, where might these feelings and beliefs have arisen?
    - How are these biases interfering with my ability to provide compassionate whole-person care to my older patients and their families?
- Open dialogue with others can facilitate self-growth and the inner growth of members in one's care-providing team. Such dialogue may occur in one's personal life or with colleagues in the work setting. Sharing thoughts, feelings and knowledge and experiences with others allows one to open one's mind and understanding to new viewpoints and information.
- Acquiring information and education about the sociology of culture can enhance understanding and help an individual to feel more prepared and effective when practicing health care in a cross-cultural situation. There are many books and articles written about this subject in the fields of health care, sociology and anthropology. Community colleges, universities and various cultural community groups offer many learning opportunities.

HEALTH CARE TEAMS

Health care teams in various care settings can also learn and grow in this area of cross-cultural caring.

- Fostering an atmosphere of open inquiry is the most important first step. Moving from a mindset of "right or wrong", "better or worse", "should be done this way" to a mindset of enhancing understanding and flexibility, "there are many ways to be" allows health care and social service providers to ask questions and share their vulnerabilities and uncertainties.
- Encouraging in-service education, team meetings and other venues to provide opportunities for learning. Sessions need not be long in order to stimulate thinking and promote the dissemination of new ideas and information. Posting an interesting article, for example, may be a way to begin. Asking questions at team meetings is another. For example, "I don't know very much about Somalia, do you? I wonder how we could get the information we need to care for Mr. Y. in a more effective way", could initiate a useful learning experience.

- Building a cultural care resource centre in the team working area. There are currently workbook type of educational resources that promote active learning.[10]
- Reflecting on the theme of "care delivery systems as culture" would be a fascinating way for teams and staff groups to begin to think about culture.
    - Do we know that we, as health care and social service providers, have been "inducted" into a culture of care delivery?
    - Can we think back to how we moved from being "just ourselves" to acquiring the values, beliefs, ways of being, language, dress, body language and other features of the culture of our profession and of health care overall?
    - Can we reflect and discuss how this "care delivery system as culture" might influence our own behaviours and how it might be seen by those patients and families for whom we care?
    - Does it open or close our minds, enhance or impede our flexibility and compassionate care?

Reflection on such questions is an exciting journey for everyone.

- Exploring attitudes, beliefs and biases with one another can be helpful. An atmosphere of trust is essential to facilitating this type of discussion. The areas to be explored are the same as those outlined in one's own personal journey.
- The qualities of sincere interest, desire to learn and desire to provide the best in effective person-centered care are the best motivators for health care and social service providers in enhancing their culturally-aware practice.
- Expanding the resource care team is important. Spiritual advisors, social workers, volunteers and linkages with various community cultural groups will enhance team education and help older patients and families feel more secure and comfortable.
- Learning from each other is a very effective way to become more culturally aware. Staff members themselves usually are representative of a number of cultures and faiths. In an atmosphere of openness and trust, it is possible to share information about cultures and beliefs and to utilize one another as "on the spot" resources. In the process, we also come to know one another better and create a more cohesive care team.

HEALTH CARE PROGRAMS, INSTITUTIONS AND ORGANIZATIONS

Members of health care programs, institutions and organizations set the tone for teams and individual staff members as they work to develop a more culturally-aware practice. Organizations can move forward in a number of ways:

- Foster a "top down" philosophy about cross-cultural care and caring that clearly states that this is valued and expected within the organization.
- Identify any particular cultural groups and needs within the surrounding community and explore together how these needs might be better met. Work with the leaders and members of these community groups regarding ways to enhance practice and care.
- Develop collaborative projects, with the cultural communities, on the selection and training of interpreters. The presence of skilled interpreters is a valuable aid to good health care practice.
- Foster the development of a culturally diverse group of palliative/hospice volunteers from which staff can draw assistance and support.
- Provide opportunities for education and educational resources so that staff members might discuss, learn and grow. This will include time to attend sessions and to be together to explore values and practice patterns and interactions with seniors and families.
- Develop a forum within the daily work situation where staff members can share experiences.

- Celebrate and recognize staff members for positive culture-enhancing practice and innovation in this area.
- Provide a well-integrated and high profile way of accommodating for specific cultural needs. This may include such things as physical space for large families, places where specific practices, rituals and ceremonies can be carried out.
    - For example, if incense, candles or sweet grass must be burned, can this be anticipated and a safe practice be developed in conjunction with the cultural leaders and the local fire marshall? If music, chanting or drums will be present, how can this be accommodated?
- Consider enhancing the presence of cultural and religious symbols in the facility to reflect inclusiveness and diversity of the community served. This can be done with murals, sculpture, plants and gardens. A "donor wall" can be another way of encouraging all community cultural groups to participate as partners within the program or facility.
- Ask communities to develop informative displays about their culture and community. Such displays might be rotated in the main lobby of the facility or might become permanent displays. There are innumerable ways to foster a heightened awareness of and knowledge about one another's culture.

CARING FOR OLDER PATIENTS AND FAMILIES

> ***" Be open in acknowledging and respecting the sociocultural variation that exists amongst people. There is a rich mosaic of humanity, and with awareness, time and an increased level of consciousness, practitioners of the health disciplines can learn to incorporate into their practice a new and more comprehensive way of seeing people".***[11]

Here are some starting points for seniors and family care:

FOCUS ON THE UNIQUENESS OF THE INDIVIDUAL PERSON[12]

- Focus on the senior, not the group. Each senior is unique. Values, beliefs and ways of being are developed from many sources including culture, religion, life experiences, reading, and education.
- Learn to think in terms of shared concerns and experiences with unique adaptations. Seek common ground while acknowledging "uniqueness" rather than "difference".[13] For example, seniors of all cultures feel grief and loss. That universal experience of sadness is shared with all other human beings. Accepting this similarity with those for whom we care, we can then ask "what are the unique ways in which this sadness and grief will be expressed and managed in this senior given his/her cultural heritage and life experiences?"

GATHER THE INFORMATION REQUIRED FOR CULTURALLY-SENSITIVE CARE

- Gain background information about the culture of the senior. Caring across cultures: Multicultural considerations in palliative care is a resource information handbook.[14] Other sources which provide information about a number of particular cultures and faith groups are listed.[15]

Again, it is important to emphasize that while such broad information about cultures can serve as very useful background, one cannot generalize to the specific. it is only from the particular patient and family that one can learn their unique interpretation and incorporation of culture, heritage, values and practice. What does their culture mean to them?

- Develop ways of inquiring about cultural matters. As a health care team, develop some questions which will elicit the information you need. For example:
    - "We want to give the best care to your mother. Are there particular things that we should do or should not do as we give care?"
    - "We would like your mother and you, her family, to feel at ease and comfortable in our setting (ward, unit). Can you help us to learn about your faith and ways of being?"
    - "I notice that your mother keeps her face covered, but sometimes her veil can be removed. Can you help our nurses in understanding this practice so that we can do what is comfortable for her?"
- Encourage seniors and family members to share information as to what is allowed or not allowed, what is comfortable or uncomfortable and what their requirements might be in the many areas that might be impacted by care.
- Gain important information from the senior or from close family members or cultural/faith leaders about specific matters that relate to caring for a senior who is seriously ill and dying. These include:
    - the religious background, beliefs, and the role of faith in the life of the senior and his or her family
    - the social and religious support systems for the senior and family
    - the lines of decision-making in the family and from a cultural perspective
    - the cultural and religious perspectives on the causal agents of illness and death
    - the cultural and religious perspectives on sanctity of life
    - the cultural and religious perspectives on the definition of death

Information in these areas will be helpful in understanding the viewpoints of the senior and family and why they may be approaching the illness in a certain way. It will have great importance when treatment decisions are being made, particularly around issues of cessation of treatment, life support decisions, cardiopulmonary resuscitation, among others.

- Try to gather information as early as possible in the course of illness and care. Particularly, try to have cultural and faith background information and knowledge before meeting with families about life and death treatment decisions. If this is not possible, acknowledge that there is a cultural dimension which may have an influence on the way that care is going to unfold.

STRIVE TO ENHANCE VERBAL COMMUNICATION WITH SENIOR AND FAMILY

- Provide on-going dialogue with seniors and families from the outset of the illness. Cultivate an atmosphere of openness and availability.
- Seek ways of enhancing verbal communication, particularly if there is not a shared language or if the shared language is limited. Often, seniors know more English language than is initially apparent. Given some time and a relaxed atmosphere, a path to some degree of verbal communication may be found. The challenge is to take time to listen, choose words that are commonly used, speak clearly and slowly, perhaps using one or two words at a time. There are many ways to develop word lists of the key required phrases which can enhance practical verbal communication. Families are often very helpful in developing such a chart. Questions about pain and pain relief, bowel care, other physical symptoms, physical needs and wants, as well as emotions can be included in the list.

REFINE PRACTICES RELATED TO THE USE OF INTERPRETERS

Although interpreters have been utilized in health care for many years, it is only recently that the complexities of their role are being recognized. Ideally, interpreters are selected and receive prior educational training in the skill of interpretation, some health and illness knowledge and language, and some sensitivity to psychosocial aspects of illness and grief. As well, they require guidance regarding issues of confidentiality. If such a trained translator is not available, these areas should be discussed prior to a senior or family interview (see preparation, below).

- Confirm that the senior and family will be comfortable using an interpreter from outside their family; ensure that the interpreter who is chosen is acceptable and that mutual understanding exists. In certain societies, people of one group may not interact with those of another and may feel uncomfortable or insulted if this occurs. This may be encountered with people from India where there is a caste system or with people where there has been a long history of ethno-political tensions between groups such as in Bosnia and other areas of the world.
- Preparation time with the health team and interpreter prior to the meeting will help insure understanding about what is to be conveyed and the goals of the dialogue. Sufficient time should be allotted to the interview with the senior or the family meeting to allow for the process of translation. The quality of translation should be accurate and unbiased.
- The interpreter will require support in his or her difficult task of conveying bad news, because he or she will become the person who actually conveys the reality to the senior and family. The interpreter may require some time to de-brief and share his/her own feelings after the interview, particularly if the interview has been emotionally-laden in content and process.
- It can be very difficult for the children or grandchildren of seniors to serve as interpreters, particularly when the process of interpreting requires a degree of role reversal or when the information to be conveyed is emotionally distressing, such as talking about diagnosis and prognosis. It is best to explore this with adult children before the interview, as they may wish to be the ones to give information rather than involving a "stranger". If they are the only ones available, young children and teens should serve as interpreters only for practical matters of day-to-day care and alternative interpretation should be sought for more serious matters.

CULTIVATE NON-VERBAL COMMUNICATION SKILLS

- Be aware of your own non-verbal communication and body language (facial expression and gestures). As when interacting with all seniors and families, strive to maintain a demeanor of respect. Be aware of your "way of being" - your caring, sincerity and respect will always be sensed by the seniors for whom you care and will do much to enhance peace of mind and trust even when words cannot be understood.

CONCLUSION

> ***"Dying is a very private and unique event for each senior and family. We should intrude as little as possible and assist as much as we can".*[16]**

The philosophy of Palliative Care and end-of-life care, being person-based, requires that health care and social service providers develop a culturally-aware practice. We are challenged to be flexible and to foster care practices that celebrate the diversity that surrounds us. Culturally-aware practice is not only very helpful to seniors and families for whom we care, but it also provides us with unique opportunities for personal growth. The following chapter on Aboriginal Issues emphasizes as well the importance for health care and social service providers to be culturally-aware when providing care. The senior at the end of life is at the centre of the care paradigm and his or her needs must be met in a way that is appropriate for that person.

SUMMARY RECOMMENDATIONS FOR PRACTICE

- Recognize the importance of culture in the lives of seniors and their families.
- Treat seniors as unique individuals with particular cultural and ethnic heritages.
- Understand how culture influences values and beliefs surrounding health and illness, including physical care, pain control, dietary and nutrition requirements, complementary and alternative therapies and other aspects of treatment and care.
- Understand the influence of culture on communication involving truth telling, the role of talking and sharing emotions, non-verbal ways of communicating, decision making and the role of family and friends.
- Respect cultural rites and ceremonial practices that accompany death and dying and grief and mourning.
- Refine institutional practices related to the use of interpreters.

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9 chapter

ABORIGINAL ISSUES

INTRODUCTION

Goals of this Chapter are to:

- provide an understanding of the beliefs and values underlying the Aboriginal people
- understand how these beliefs and values influence illness, suffering, healing and end of life
- help health care and social service providers provide respectful and culturally-sensitive care to Aboriginal elders

While the previous chapter explored culture in general, this chapter will look specifically at Canada's founding culture, that is the Aboriginal people and their diverse views on end-of-life care issues. For the Aboriginal people, the circle of life is the basis for their belief system. Humans are born, they live and they die, and thus the circle of life continues. This chapter will explore this belief of the circle of life and what it means in relation to more specific issues of end-of-life care for Aboriginal elders.

In Canadian society, there is a tendency to view Aboriginals as a homogenous group. However, they represent one of the most culturally and linguistically diverse segments of our population. In general, the term Aboriginal refers to five groups of people:

- First Nations: Status Indian, as defined by the Indian Act
- Non- Status
- Inuit (though the Inuit do not consider themselves Aboriginal)
- Metis: persons of mixed ancestry including Aboriginal
- Innu: Native people of Labrador

Within these groups, there are 73 different tribal groups, and 11 different language groups made up of approximately 51 different languages and dialects.

While it is difficult to gain a definitive census regarding the number of Aboriginal people in Canada, the most accurate numbers available at this time are based upon the Indian Register of the Department of Indian Affairs and Northern Development (DIAND). As of August 31, 1997, there were 622,024 people registered Indians and Inuit in Canada not including the Metis.[1] According to the 1991 Census, there are just over one million Aboriginal people in total. Of these, 75% claimed to be of North American Indian ancestry, 20% of Metis ancestry, and 5% of Inuit ancestry.

Health statistics for Aboriginal peoples are available for First Nations and Inuit people only, and generally these statistics are used for other Aboriginal groups. While the number of seniors will grow in Aboriginal communities, the picture of this aging population is not the same as in the general population. In contrast to the general population in Canada, the First Nation and Inuit population tends to be young: 38% are under the age of 15 and only 3-5% are over age 55.[2]

The definition of 'senior' is different within the Aboriginal community from that of the general Canadian population, being defined as persons 55 years and over.[3]

- Older Aboriginal persons prefer to be called "elder" as opposed to "senior".[4]
- The life expectancy for Aboriginal men and women is, respectively, 13 and 11 years less than the general population.[5]
- Just over half, 55%, of Aboriginal elders claim to speak their Native language. Cree, Inuktitut, and Ojibway are the most prevalent languages today.[6]

There are approximately 2,250 reserves in Canada divided among 606 bands. Most of the communities are in rural areas or in remote or isolated communities. Inuit communities are small and scattered throughout the north. Most live in the eastern and central arctic regions of Nunuvut.[7]

The health status of Aboriginal people is highly compromised. Compared to the rest of Canada, the rate of disability is higher for all ages.

- Disability is found in 30% of Aboriginal people.[8]
- In 1989, in the Sioux Lookout area, almost 80% of those over the age of 65 reported a disability.
    - 20% of these elders were severely disabled, the bulk of problems relating to hearing, mobility and agility.
- Problems that have been found to aggravate disability and chronic illness in Aboriginal communities are tobacco, alcohol and substance use. Alcohol plays a big role in accidental deaths, unintentional injuries, suicide, homicides, and Fetal Alcohol Syndrome (FAS). Resources were found to be lacking in rehabilitation, an informal health care system, and housing and physical access to facilities.[9]

Historically, infectious diseases were prominent among Aboriginal and Inuit people. Today, the picture of chronic illness pervades.

- The low rate of heart disease among the Inuit is associated with a diet that is high in fish and healthy fats.
- The Inuit have a higher incidence of respiratory diseases such as tuberculosis and chronic lung disease than First Nations, but smoking is responsible for higher rates in both groups compared to the general population.
- First Nations have high rates of diabetes and other conditions that co-exist with diabetes as well as the complications of diabetes. These complications of diabetes, kidney disease, heart and circulatory disease, blindness, amputations, nervous system disease and birth defects are debilitating. However, the rates of diabetes among the Inuit are changing as their diet changes to modern foods.[10]

Although the First Nations of Canada encompasses very diverse cultures with distinct customs and myths that govern the behaviour of the individual within these groups, there are beliefs that are common to all. For instance, an examination of the rituals, customs and myths of First Nation societies provides a greater understanding of the morals and values that govern behaviour.

- The tenet within these societies is that the exercising authority of the myths and customs comes from a source existing externally from the group or individual. This authority lies in the Creator.
- In these myths, there is little or no distinction between the animate and inanimate. There is an understanding that humans are a part of nature and as such, nature is given equal respect. All life is addressed as "Thou" and given equal respect and value.
- These values are transferred to daily life ensuring that all members are given equal respect and value within the community. This concept reflects the inclusive philosophical and psychological view of First Nations people.[11]

Knowledge of the customs of the society imparts what constitutes acceptable behaviour within that society and, as well, ensures continuity. Conformity to custom is a matter of religious obedience that is consistent with the accepted moral standards of the people. First Nations customs:

- originate with the Creator, investing individuals with authority and power that obliges them by conscience to obey
- form part of a larger plan for the survival of the people

This belief system is based upon the understanding that humans are a part of nature and are dependent upon nature for survival. It follows then that all individuals within society are interdependent for the survival of the whole. This ideology also implies that as a member of the group, each individual possesses not only inalienable rights, but also obligations to the society. The recognition of obligations that exist in conjunction with the rights of the individual forms the foundation for compromise that acknowledges the dignity of others and ensures the continuity of not only the culture, but of the group itself.[12]

The values that dictate behaviour within First Nations Cultures may be found within an Ojibway Legend passed on by members of the Midewewin society about the Path of Life. According to this story, by leading a good life and following the Path of Life, we will be given admittance to the Land of Souls at the end of our life.

SPIRITUALITY*

When examining First Nations society, there is a tendency to compartmentalize its components. However, this method does not lend itself well to the examination of First Nations society. To a large extent, this is due to the structure of First Nations society itself.

- Unlike non-Indian society, there is no separation between church and state, church and the individual, or human and nature.
- There are no teachings that dictate how or where to communicate with the Creator; spirituality is a very personal thing. It is something that is within the individual and is taught from the day one is born, influencing one's actions, words, beliefs and customs. The ceremonies and traditions within the culture are simply a manifestation of this spirituality.

There is a common belief within First Nations society that the Creator provided a set of laws by which to live. These laws, based upon common human values, are found in every major religion of the world. However, what sets First Nations apart is that these laws are not separate from the individual but are rather internalized, influencing every aspect of the individual's behaviour. In general terms, these concepts include:

- respect
- honour
- courage
- kindness
- sharing
- acceptance
- communication

These concepts are present in interactions between humans and also between humans and nature. The worldview of First Nations dictates that man is a "part of", rather than "apart from". In addition, this also lends itself to the

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* Additional information on this topic is in Chapter 7.

understanding that the world is a circle and all things both animate and inanimate are part of a greater whole. Thus, there is a belief in the unity of all living things, both animate and inanimate.

The circle is very representative:

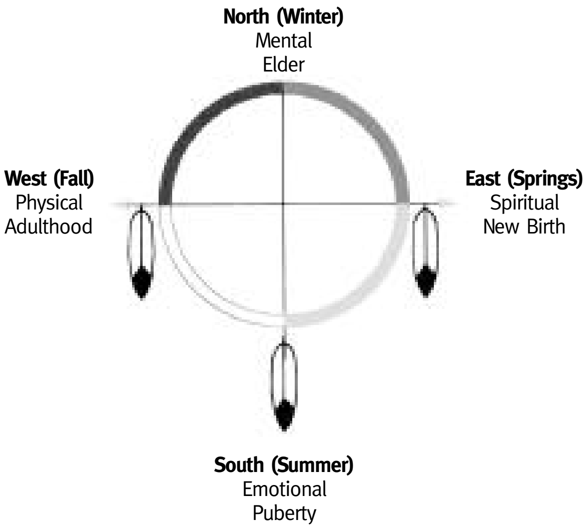
- it symbolizes Spirituality
- it represents the cycle and seasons of life
- to the East, where the sun rises and the spring promises new life, is the realm of new birth and childhood
- to the South, the origin of the warm summer winds is the realm of puberty
- to the West, as in nature, when summer must give way to fall and the preparations for winter must be made, the land of the setting sun is the domain of adulthood
- to the North, adulthood gives way to old age, just as the fall is followed by winter. However, similar to the practice of making preparations during the earlier stages of the year to ease the hardships of the winter, the senior years of First Nations people, if they have lived a good life and conducted themselves according to the laws of the Creator, will be made easier.

At each stage in one's life, myth, ritual, and ceremony are used as a means of helping the person adjust to a new spiritual transformation. Within this circle, it is understood that this cycle is continuous and the end of life is simply a transformation to another spiritual existence, one that is dependent upon how well this life was lead.[13]

The concept of balance is inherent within First Nations society:

- Balance plays a crucial role within relationships among humans, humans and nature, humans and the spiritual world, and the individual him or herself.
- There is a perception that the universe is an intricate meshing of personalized powers great and small, beneficial and dangerous, whose equilibrium is based upon reciprocity.[14]
- There is an understanding that humans are not only physical beings, but also spiritual, mental, and emotional beings. The medicine wheel teaches that these four aspects to our nature must be equally developed in order to be a healthy well-balanced individual.[15] Thus, it is understood that all four aspects can affect each other and imbalance in one area can lead to problems in another. (See Figure 1).

Figure 1: Medicine Wheel



- The four colours of the sacred circle - black, red, white and yellow - are often viewed as the colours of humanity.
- The colours indicate that all humans are part of the circle and should be given equal respect and honour. While people originate from different corners of the world, all have their own gifts and own special knowledge to strengthen the circle of humanity.[16]
- All the rituals and ceremony are based upon maintaining this balance for the individual and for the society. Honour and respect is given in return for blessings or gifts received.
- This belief in balance through reciprocity gives rise to what has been termed the "law of hospitality". The giving of gifts and hospitality is viewed as a moral and diplomatic obligation; often gifts are given when people come to visit, during ceremonies, provide a service, or seal an alliance. Among other things, gifts have the ability to wipe away tears, appease anger, and raise the dead - gifts are metaphors for words.[17] More importantly, gifts and hospitality are a sign of respect.

Respect is central to the societal and belief systems of First Nations. The ceremonies are manifestations of this concept. Respect also shapes the behaviour of members within these societies. As stated earlier, all life and all beings are shown respect through an individual's actions.

While the medicine wheel is not a universal concept among Aboriginal and Inuit people, its concept of the circle of life, balance, harmony and relationship is. The two experiences that all human beings have in common are birth and death. As with any living thing, humans are born, they live and they die, and thus the circle of life continues. How death is viewed and, in some cases, celebrated is what sets individuals apart within the human community.

THE ROLE OF ELDERS WITHIN FIRST NATIONS SOCIETY

The Path of Life teaches to honour and respect our Elders for they are the recipients of the gift of long life from the Creator. If they are slow, feeble and sometimes infirm, it is our responsibility to care for them, listen to them, help them and be patient; this is very important because someday we too will be old.[18] Within First Nations societies, Elders are the keepers of the cultural knowledge.

- Elders serve many capacities within First Nations communities as educators, family matriarchs/patriarchs, child-care providers, political, cultural and spiritual advisors, and are often viewed as the community conscience in many of their home communities.
- In return, Elders are given respect, not only within the family, but also within the larger community as a whole.

Elders within First Nations societies are viewed as a valuable resource, as they are the links between the past and present. They often serve as valuable members on committees and are consulted during the decision-making processes in many First Nations communities. It is through this community service that many Elders are able to remain active and involved in their community well beyond the age of many seniors within the larger society.

> *"That's how my mother trained me, I went to many, many Elders in my lifetime. Some Elder's (sic) I listened to them and I respected their views but not necessarily use the way they looked at life. I picked out what I could use and sorted out what I respected. Today I encourage young people to do the same thing, to go to many Elders' (sic). It only costs you Tobacco that's all a pinch of Tobacco, one cigarette. Go seek information because that information is there it's like a computer and if you don't go to those Elders' (sic) they go with that valued information".*[19]

Respect for Elders within these communities is shown in a number of ways. There is a code of conduct that is observed by members of these communities that can serve as a guide:

- Younger people are expected to listen to the Elders. Even if they do not agree with their opinions, they cannot interrupt an Elder when he/she is speaking.
- Younger people are expected to look after the needs of the Elders; for example, during any feasts, the Elder is the first to be seated and served by younger people.
- The provision of hearing devices and, in some cases, interpreters during large gatherings, such as band meetings, will help guarantee that the Elders not only hear but also understand the proceedings.
- Many First Nations have programs in place to assist Elders to remain in their homes. Home care providers come into the home to do the heavy house and yard work for the Elders free of charge, and as well, other services such as the provision of wood, water and garbage pick-up are provided free of charge. Community Heath Workers provide transportation and additional assistance to Elders within the community.
- Aboriginal people value their independence to the extent that they will ignore health problems in order to stay closer to home. The history of treatment of illness and of communicable diseases in remote and isolated areas is that people and children were removed to southern hospitals. Some people never returned home. Thus, nursing homes are still viewed by Aboriginal people as places where one goes to die.

The Elder role is making a rapid comeback in Aboriginal communities where Elders can be role models and teachers. Many have been sought to contribute to recollections of the treaties, community development and self-government. There is a reappearance of interest in alternative methods of traditional healing, medicines and healers. There is an urgency to gather information to preserve and record our history. Increasingly, Elders are encouraging the youth to get an education and to develop skills in technology.

The Aboriginal and Inuit Elders come from a generation which has experienced multiple losses.

- The assimilation of Indian people from the mid-1800s to early 1970s removed them from the influence of family and community to residential schools, so that they could become 'good productive citizens'.[20]
- This experience resulted in the loss of language, culture, spirituality, traditional values and customs, food, and traditional sustainability. It was a process of disassociation of self through loss of self-identity, group identity and group support, thus stripping people of their Native pride.
- Individuals lost contact with their families, and often did not know their siblings because they were removed from their families for months or years at a time. In some cases, children were moved long distances away.
- The schools tended to be run along a military and Christian ideology, with a belief in corporal punishment. Physical, sexual and emotional abuse were rampant, and many people were affected for life.
- Observation and studies have come up with the term 'residential school syndrome' which embodies the following: alcoholism, difficulty forming close or intimate relationships, poor parenting skills, and poor self-esteem. Graduates of the residential school system felt alienated and marginalized when they came into contact with their own people and in the mainstream community.
- Despite the negative residential school experience, many Elders are not traditional and they value Christianity.

FAMILY STRUCTURE WITHIN FIRST NATIONS SOCIETY

First Nations' family structure is based upon the extended family rather than the nuclear family. It is common to find multigenerational households within First Nations' communities. This allows both the Elders and infirm to stay in their home surrounded by family for as long as possible. Often within this setting, a close family member, such as a child or grandchild and in some cases a spouse, will be the primary caregiver in the home and act as a liaison between the rest of the family and health care and social service providers.

The family:

- There is no distinction between 1st and 2nd generation relations. For example, a child's great-aunt would not be referred to as such, but rather referred to as Grandmother. The term uncle and aunt are not limited to parental siblings, but are extended to parental cousins as well. In addition, adopted relatives are also recognized with no distinction between natural and adoptive relatives. There are little or no differences between the treatment and respect given to a close blood relative and that given a more distant relation.

As result, it is not uncommon for a large extended family to gather when there is a health crisis within the family. This demonstrates respect for the ill or dying individual and shows support for those family members most affected by the crisis.

In an institutional setting, it can be confusing for health care and social service providers to understand who to deal with regarding matters directly affecting the ill person. The best advice in this situation is to ask the family to appoint a spokesperson with whom the health care and social service providers can use as a liaison between family and service providers. This individual can also give the health care and social service providers guidance regarding special arrangements including any ceremonial and personal information regarding the Elder who is ill.

TRADITIONAL HEALING & CEREMONIES AMONG FIRST NATIONS

Ceremonies and healing are viewed as very special gifts given by the Creator to a chosen few. Just as there are a large variety of languages among First Nations, there are also many ceremonies and healing methods that have been given to First Nations. Moreover, there are tribal-specific ceremonies. This section will present a general overview of various traditions.

PERCEPTION OF ILLNESS

The historical view of the causes of disease and illness, that of a long and healthy life being taken away by the Creator for some offense, still holds true today within many First Nations cultures.

- Illness may be viewed as a failure of the individual to live "a good life", that is by living according to the guidelines set forth by the Creator.
- There is also a belief that someone whom the individual slighted can "send" illness. Many First Nations cultures share this belief in "bad medicine" and "good medicine". While it is believed that all medicines are good in nature, it is how the medicine is used that determines which category it falls into. According to a Cree Elder:

> *"The way I explain is that all medicines were given to us as Indian people to be good medicine, and a lot of times people mix medicines the wrong way and it's becomes negative. But all medicines were meant to help our Indian people in this world and that's the way I look at it."* [21]

HEALING METHODS

In cases of "traditional" people or families, when a family member falls ill, healers or "Medicine Men" are brought in by the family to intercede between the ill person and the spirits, including the Creator. In some cases, this may be a last resort, i.e., when traditional western medicine fails or there is little improvement in the health of the individual.

Within First Nations societies, individuals popularly know as Shamans, Medicine Men or Women, are highly respected. These individuals:

- possess special gifts for communicating with the non-material world
- intercede on behalf of the people between themselves and the spiritual world[22]
- treat disease, in some cultures, with special herbs and roots and are known as herbalists
- are trained from an early age in the use of the medicines and the ceremonies that go along with them

While it is unlikely that health care and social service providers within an institutional setting will be directly involved in the ceremonial elements of healing, they may come in contact with the medicines and ceremonial and spiritual items kept near the ill Elder. If unfamiliar with the item, it may be worthwhile to discuss its importance with the Elder and family. For example, in many First Nations societies, it is important that women who have their menses - referred to as "their time or moon" in First Nations societies - do not come into contact with these items. At all times, it is essential that the items are treated respectfully. A valuable guideline in this case is to remember if you do not recognize or know what it is used for, leave it alone. Common healing tools include:

- medicines in the form of teas
- feathers
- cloth
- special stones
- sweetgrass, cedar, or sage
- pipes

With many tribal groups including, but not limited to, the Dakota, Nakota, Lakota, Ojibway, Saulteaux, and Cree, the pipe is of special significance. Very often, a pipe ceremony is used in conjunction with other healing ceremonies. The smoke of the pipe carries the prayers of the people directly to the Creator. In addition, it is believed that in the presence of the pipe, nothing but the truth may be spoken.

END-OF-LIFE ISSUES FOR FIRST NATIONS

Older people in First Nations make up only 3-5% of the population as compared to 11% in the non-Aboriginal population.[23] Aboriginal people die at a younger age than non-Aboriginals. Causes of death include:

- diabetes complications
- heart disease
- cancers
- stroke

Older Aboriginal and Inuit people are more likely to live in rural and isolated areas. However, increasing numbers of Aboriginal people are moving to urban areas because of a lack of facilities closer to home. This fact speaks to the need for an understanding of the following specific cultural care issues for Aboriginal elders at the end of life.

HISTORY TAKING

- Admission histories tend to be extensive and are better done in segments. Many items can be answered through observation or simply asking the family caregiver.
- Elders are quite sensitive to personal questions and consider them impertinent. For example, questions pertaining to bodily functions such as elimination are considered intrusive. It helps to explain the importance of such questions. In some cases, one will have to use lay terms.
- Aboriginal patients may refuse care from health care and social service providers because they "ask too many questions". Aboriginal persons may never have had a reproductive history review or examination.
- Discussion of sex is taboo among many Aboriginal groups.

PAIN MANAGEMENT*

People generally have a high tolerance for pain. They will not complain or ask for help. It is important that health care and social service providers recognize that it is a cultural characteristic to not show pain. The onus is on the service provider to assess the manifestation of pain and non-verbal behaviours and to listen to relatives or friends.

> *"My family experienced this with my father. He was a very patient man. He rarely discussed personal matters. Whenever he had something to say it was sure to be profound. He had a great sense of humour. Diabetes was diagnosed following a stroke at age 64 . Although he was not expected to walk again his sense of determination and independence motivated to regain mobility. He had limb amputations and tolerated a great deal of pain. Despite the fact that we informed the nurses that he will not ask for anything or complain, the nurses ignored our pleas. He was made to suffer and was not given any analgesics. The pain was evident on his face."*[24]

- Aboriginal elders do not want to "bother" health care and social service providers and expect that these people are the experts. Therefore, they expect these service providers to apply and intervene with their observations and clinical knowledge. This means that it is necessary for the health care and social service providers to read non-verbal signs of pain, touching, holding, increased pulse, tensing, changes in facial expression, holding of breath and irritability, among others things.
- Belief plays a critical role in healing. As many older people were raised in two systems, Christianity and Native Spirituality, they may take medicines, yet ask for an Elder or a healer to visit. They will use prayer, burning sage, sweet grass or cedar. There may be use of group support of listening, sharing and smudging.
- Some interventions will call for compassionate gestures such as offering a cold towel to wipe the brow. Someone should stay with the person in pain to comfort and sometimes just to hold the elder's hand. Offering a word or two and showing recognition is comforting. Some elders have described certain nurses as "so good" because they talk to the individual.

PERSONAL CARE

- Aboriginal people have a high sense of modesty and will reluctantly let others provide personal care. Health care and social service providers need to be aware of this. They prefer someone of the same sex to provide personal care. Usually, they will not allow someone from their own family of the opposite sex to provide such care, although they will accept a spouse.

> *"Not everyone is able to ask someone for their help. If you see he needs help and you want to offer your care, simply ask him if he would like you to contribute."*[25]

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* Additional information on this topic is in Chapters 3 and 7.

You will have to respect the individual's decision whatever that may be.

HOUSING AND TRANSPORTATION

- Housing is inadequate for most Aboriginal seniors.[26]
- Access for disabled people remains a challenge in households where safety devices are not in place to assist with the activities of daily living.
- Other amenities that may be lacking include water supply, running water, fuel for heating, adequate plumbing, and transportation for disabled seniors. Transportation affects access to medical services, supplies and food. Access is by air only in some areas, and the cost of transportation is very high. Poor transportation and cost in many communities make visiting difficult for family and friends when people are hospitalized outside the community. People do not want to leave their community.

CHALLENGES

- First Nation people are hospitalized two to three times that of the non-Aboriginal, one reason being the lack of continuing care. Often, Inuit and Innu are institutionalized because of lack of facilities for treatment and care.

The language and cultural differences encountered in institutions place additional stress on the individuals concerned.[27]

- In accessing services outside the community, many elders reported experience of discrimination at the interface of health and social services.[28] Elders feel alienated by a medical world, which often does not understand their language or their ways. As a result of communication difficulties, Aboriginal people will not return to the health care service, may not comply with treatment plans and instruction, or will refuse to let health care and social service providers into their home.
- Many studies are inaccessible to Aboriginal and Inuit people because literacy levels are beyond their comprehension.
- It is important to include Aboriginal people in research studies.

Aboriginal people have difficulty accessing the help they need because they are unaware of available services.

- Finding support sometimes becomes a matter of traversing the bureaucratic system of federal, provincial, municipal and local band governments. There is a lack of available and coordinated services.[29]

The Department of Indian and Northern Affairs and Health Canada provides adult care services on reserve, and this enables elders to stay in their communities and to have care provided by their own people. Home Care began a developmental stage in First Nations and Inuit communities in 1999 with community/home supports being offered locally and with nursing care being provided from outside the community through provincial Home Care programs.

- Non-Insured Health Benefits (NIHB) is one program that can be accessed by First Nations and Registered Indians for eye care, dental care, medications, medical devices, medical supplies, and medical transportation.
- At times, socio-economics play a factor in persons being compliant. Where people have to pay up-front for drug benefits or other services, survival will supersede medical needs and food and shelter will take precedence.

Helpful Hints for Care Provision

- Health care and social service providers should learn more about Aboriginals through personal contact. Talk to people.
- Aboriginal elders need to feel that they can "have a say" about their needs.
- Better communication is vital. Use language that Aboriginal elders can understand. Listen.
- Information is important, especially in hospital. One needs to know what services are available within the community. Transportation issues may arise.
- Health care and social service providers need to be aware that it is difficult for Aboriginal people to ask for information.
- Offer help instead of asking whether people need help.
- Health care and social service providers need to know the importance of relationship building before coming to the Aboriginal community.
- Spiritual care using Aboriginal language is needed.
- Provide services which elders cherish such as hairdressing.
- Respite care for the caregiver is needed.
- The implementation of sharing groups could be helpful.
- It is helpful for health care and social service providers to know that most advertising and public relations is through word of mouth.[30]

COMMUNICATION

Effective communication patterns between the Aboriginal Elder and the health care and social service provider are important for end-of-life care. Some common Aboriginal methods of which to be aware include:

- different non-verbal communication styles, e.g., lack of eye contact during interaction
- "yes" or "no" answers to questions - This may be related to the fact that the Aboriginal does not understand or want to speak English. They may feel that they can express thoughts better in their own language.
- Silence - It is not uncomfortable for many Aboriginal people. It is generally considered impolite to interrupt a person who is speaking. If one is interrupted, he/she will wait until the other person finishes before beginning to speak again.[31]
- indirect and subtle communication
- storytelling
- humour

THE PROCESS OF DYING

Often, death is perceived as a reunion with other family members. Many people relate a dream where a mother or departed family member is beckoning the elder to join them. Death will be approached as another stage in the circle of life.

When difficult decisions need to be made, the responsibility of the health care and social service providers is to ensure that the family understands what is happening.

It is important not to assume that all Aboriginal persons hold traditional beliefs. Many were led to renounce native spirituality through residential school indoctrination or may have been raised by non-aboriginal foster parents.

THE HOLISTIC APPROACH

When one is dying and in pain, the pain may disturb mental faculties, feelings of abandonment and rejection may surface and the spirit may give up. This aloneness may be felt by the individual, by family and friends who cannot visit and the community. The importance of cultural care must be recognized as it affects the physical, mental, emotional and spiritual aspects of being.

LEGAL AND FINANCIAL ISSUES

The socio-economic conditions of Aboriginal people are low:

- Most First Nations and Inuit elders live in poverty with annual incomes in the range of $5,000 to $10,000.[32]
- They receive the OAS and GAINS.
- In many cases, because of high unemployment rates on the reserve, elders are the main source of income for the family. Financial abuse by others is a possibility.
- Most live with other members of the family, and some are caregivers of disabled children or grandchildren.
- Many die in poverty without enough money to pay for their own funeral. Some people may make wills for their possessions. Retirement benefits are virtually nonexistent, and the majority of people are too poor to think of a Registered Retirement Savings Plan. They have no pension plans unless they have worked off the reserve.

Some elders, as well as their family and health care and social service providers, are unaware of the federal Guaranteed Income Supplement (GIS) and the Provincial Guaranteed Annual Income Supplement (GAINS) and many need to fill out income tax returns to qualify for these benefits.

Additionally, other legal issues confront caregivers:

- Isolated elders may have no power of attorney.
- Elders may not have enough money for the public trustee. This probably occurs more often in urban areas. There are associated and unattainable costs to obtaining a public trustee. Those who cannot afford a public trustee are vulnerable to exploitation by caregivers, family, or others.
- Abuse is very difficult to prove. In some cases, one may be aware that elders are losing money, but when investigated cannot find proof. Reporting abuse is a problem for elders, families, friends, and health care and social service providers because of a fear of reprisal. Instructions for wills are often verbally stated, as are wishes about funeral and burial practices, and substitute decision making in regards to personal care and life support.

DEATH & BURIAL*

Burial customs and traditions vary between culture groups and sometimes from community to community. For example, while it is common for wakes to be held, the length of time, the duties of participants, the way they are conducted and the ceremonies connected to them varies between groups. The information presented here is intended to be general in nature and draws heavily from the customs and traditions found within the Prairie cultures. Often traditional customs exist and are incorporated into the Catholic or Protestant services.

- As stated earlier, it is not uncommon for the extended family to gather together in the hospital, hospice, or special care home during health crises. Upon the death of the afflicted person, it is also common for members of the community to join the family during this time of grief both at the institution and in the home. This is done both as a sign of respect and support for the deceased elder and for the family:

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* Additional information on this topic is in Chapter 7.

> *"If we all learn to share with one another, share when something happens, go and give them a hug, tell them you're glad or sorry for them. Make them feel like you really are sharing with them. Because you don't know the strengths you bring to a person that has lost a loved one, just by being there and giving them a hug and sitting with them for awhile. This is where the strength comes from and this is what sharing is all about."*[33]

- It is important that the immediate family look after the collection of the personal belongings of the deceased elder. Often, the time taken to do this is the first step in the healing process. Allowing the family to do this in private is especially important when traditional healing methods have been utilized, as there may be items of special spiritual and ceremonial significance that must be disposed of in special ways. In addition, these personal effects must be gathered for distribution during the give away ceremony that often follows the burial.
- The days between the death of a loved one and the Wake or funeral are often spent in the home. During these days immediately following the death, in many cultures, the immediate family is prohibited from leaving the home, as this time is spent in prayer and remembrance of the one who has passed on. This is in addition to planning the funeral and preparation for the give away and feast that follows the burial. Often, other family members will look after the funeral arrangements and act as liaisons between the funeral home and the immediate family.
- When visiting the home of the bereaved elder, it is common for all visitors to be offered a lunch and other small gifts of hospitality, including cigarettes. It is important that these gifts be accepted, especially the tobacco, as very often the offering of food and tobacco is a sign of gratitude from the family for honouring both them and the deceased elder.

THE WAKE

Within many First Nations cultures, the wake is held the night before the burial. However, due to cultural and regional differences, the duration of the wake can vary from one to four days. This is a time for both friends and family to come together to spend time with the one who has passed on. During the wake, honour songs are sung, prayers are offered, and stories of the deceased elder are shared. In addition, a fire is kept burning for the duration of the wake. According to Ojibway tradition, the purpose of the fire is to keep the soul warm during it's transformation from one state to the next and moved from one dimension to the next.[34]

As with many other First Nations customs, food plays an important part. Often a community meal is shared consisting of favourite foods of the deceased elder. As mourners arrive to the wake, they are invited to sit and share a meal. This may be repeated on the hour as new mourners arrive to the wake. At each serving of the meal, a place may be set and kept empty to allow the soul of the deceased elder to enjoy a final meal with friends and family.

- The wake is not only an opportunity for the living to bid farewell to the deceased elder, but also an opportunity to celebrate his/her life. It is a time of both laughter and tears and, to many First Nations people, it is an important first step in the healing process for those who are bereaved.

> *"I couldn't imagine not having a wake for someone I loved who passed on. When my Grandpa died, his wake was my chance to spend one last night with him, even though I knew the body in that casket was only a husk, that his spirit was no longer with me. It gave me a chance to say my good-byes and to share the memories that I had growing up with him with the friends and family that knew and loved him. It made the pain of loss more bearable by listening to their memories of him and to*

> *know that others shared the love and pain that I was feeling at that time. Having the wake gave me the extra time that I needed to say good-bye, to let go, and also gave me time to realize how lucky I was to have someone like that in my life and to remember the many gifts that he left with me."*[35]

BURIAL

- Sunrise on the morning of the burial is often marked with a pipe ceremony. Prayers are offered by the participants for an easy journey for the soul of the deceased and a lessening of the pain of loss for the family. If it is the wishes of the family, a Priest or Minister may conduct a Christian burial service later in the day.
- The services at the graveside are conducted in a number of ways. Often it is a combination of Christian and Traditional First Nation rites. The grave is purified and the body lay to rest. In many communities, the final circle of the grave is lead by the family with each person at the graveside throwing in a handful of dirt upon the coffin.
- After the burial, as with mainstream society, mourners gather for a final meal. In addition to the sharing of this meal, the family will often distribute the personal effects of the deceased elder to the friends of the elder. However, in some communities, this give away is not conducted until four days after the burial, during the final burial feast, after a year has passed, or, in other communities, not at all. This custom of gift giving arises from the reciprocal nature of First Nation society; the gifts are a thank you to the friends of the deceased elder for their friendship and support to the elder during his/her lifetime and their support to the family during a time of need.

MOURNING

Following the death of a loved one, many family members will go into a period of mourning. This may consist of a period of mourning for one year following the death of a loved one.

- The widow/widower may not be allowed to look upon a member of the opposite sex for one year.
- Very often, the bereaved individual will give up activities that he/she may have shared with the deceased, e.g., dancing.
- The bereaved person may not participate in social activities within the community during this period unless the Elders and Spiritual Leaders of the community invite him/her.

Within First Nations societies, there is a tremendous significance attached to hair.

- As well as being spiritually significant, long hair is a symbol of an individual's choice to follow the traditional ways
- It is a sign of status and wealth, especially among many nations of the Pacific coast (Tafoya).
- Upon the death of a loved one, bereaved persons may cut their hair as an outward manifestation of their grief.
- As the hair grows, it is a sign that the grief is easing, that they are slowly letting go of the elder who has died and that their bodies are preparing for a life without that person.
- Furthermore, the cutting of the hair is done as an offering to the spirits to assist the soul of the deceased elder for an easy transition from this world to next.[36]

The grieving process is important to the mental and spiritual health of bereaved family and friends. Many traditions stress the importance of a need to transform grief from a negative experience to a positive one. The entire mourning period celebrates the elder's life, not only the death.

After the period of mourning has passed, in many communities it is customary to celebrate the return of the bereaved individual into the community. Often a feast of celebration will be held and the bereaved individual will be welcomed back into the community. At the end of this period of mourning, all taboos associated with mourning are lifted and the individual is free to live the remainder of his/her life the way he/she chooses.

GENERAL PRINCIPLES

As presented earlier, within First Nations society, there are a set of principles that are believed to have been handed down to First Nations from the Creator. While these principles are not unique to First Nations cultures, they serve as a valuable guide for caregivers for the care of First Nations elders:

1. Respect: Respect the individual and his/her beliefs and customs.
   - Spirituality, whether it is manifested in traditional First Nations ways or as mainstream Western religions, must be respected.

2. Honour: Honour the individual.
   - This is shown in a myriad of ways including honouring wishes to follow or not follow traditional ways.

3. Courage: Never be afraid to ask questions about the things you do not understand.
   - If you need guidance on how to deal with a specific situation, ask an Elder or a traditional person. Elders are a storehouse of rich knowledge, understanding, traditional wisdom and guidance.[37]

4. Kindness: Show kindness to the people around you and those under your care.
   - Kindness may be shown in a number of ways such as taking the time to listen, to take time out of your busy day to sit with the ill elder, to assist him/her. Being kind to another person is a sign of respect and honour.

5. Acceptance: Accept that you are human, and do not have all the answers. Accept that there are things in this world that you cannot change. Accept that all persons are not the same and accept the differences.

6. Communication: Take time to communicate not only with the persons under your care but also the people who are important to them.

CONCLUSION

Most importantly, do not assume that all First Nations people are the same. Some choose to follow the traditional ways while others do not. These choices do not make the ways of the individual or the community any less valid or any less First Nation. Just as individuals within the larger community follow different paths, so do individuals within First Nation society, sharing in the circle of life.

Through understanding the beliefs and values of the Aboriginal people, end-of-life care can be provided in a sensitive and appropriate manner. As mentioned in the discussion on Culture, it is the senior who is dying who is at the centre of the end-of-life care model. Hence, the health care and social service provider must respect the Aboriginal elder's beliefs when providing end-of-life care. In this way, it can become an enriching and enlightening experience for those not accustomed to the Aboriginal ways.

SUMMARY RECOMMENDATIONS FOR PRACTICE

- Recognize the importance of respect, honour, courage, kindness, sharing, acceptance and communication to Aboriginal peoples.
- Respect Aboriginal beliefs, values, rituals and customs.
- Recognize the diversity among Aboriginal peoples.
- Honour the privacy and modesty of Aboriginal elders.
- Involve traditional healers and interpreters in the treatment and care of elders as appropriate.

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chapter 10

CONTINUING CHALLENGES

Seniors who are dying should be able to expect and receive competent, comprehensive and compassionate care that offers dignity, self-determination and relief of suffering. Such care is supportive of an optimal quality of life until death occurs and during the period of bereavement for the family. This GUIDE:

- Provides direction for health care and social service providers and family members of seniors who are dying
- Represents a tangible move to better integrate the disciplines of geriatrics and palliative care
- Recognizes the inevitability of death in later life from a variety of diseases and disorders that are chronic and progressive in nature
- Offers effective approaches to end-of-life care for seniors that recognize the centrality of ethics, culture and spirituality
- Promotes the maintenance of autonomy and self-determination among seniors and their families

Challenges to the provision of high quality end-of-life care for seniors will, however, continue. Rapidly changing scientific, social, economic and political environments require continuous reconfiguration of health care policies and practices. Designated funding is needed to bring together seniors, policy makers, health care planners, practitioners, educators and researchers with the purpose of improving end-of-life care for seniors. The following challenges and recommendations for action are presented with the intent of increasing community capacity to provide for optimal end-of-life care for seniors, now and in the future.

Challenge 1:
To encourage collaboration among disciplines, settings and providers.

Rationale:

The disciplines of geriatrics, gerontology and palliative care, in large measure, work in isolation from each other. Collaboration and continuity of care among disciplines, settings and providers continue to be problematic.

Recommendations:

- Develop programs that are grounded in interdisciplinary practice.
- Capitalize on the substantial developments that the various disciplines and professions have made with respect to their specialty.
- Foster the development of collaborative relationships among disciplines, settings, and providers.
- Develop strategies that bring together seniors, health care and social service providers and researchers in the areas of geriatrics and palliative care to ensure that seniors who are dying more predictably receive competent, comprehensive and compassionate end-of-life care.
- Create a cadre of personnel with expertise in aging, palliative care and end-of-life care to provide expert consultation and role modeling in the delivery of end-of-life services for seniors and their families.
- Ensure a working environment that is supportive for health care and social service providers who strive to provide an optimal quality of life for seniors who are dying.

Challenge 2:
To increase public awareness about end-of-life care for seniors.

Rationale:

An informed public is essential for the development of policies, practices and programs that will improve end-of-life care for seniors.

Recommendations:

- Encourage public debate to clarify individual, community and societal perspectives about end of life issues and the best approaches, including palliative care.
- Support frank and sensitive communication about end-of-life care among seniors, their families, health care and social service providers and the public at large.
- Organize public forums, workshops, seminars, consensus conferences, and other venues for developing a public and professional agenda to improve end-of-life care for seniors.
- Inform seniors and their families about issues that are central to the provision of end-of-life care, especially about options regarding treatment and care and their risks and benefits.
- Develop and evaluate educational initiatives to ensure that seniors and their families are aware and knowledgeable about end-of-life issues, the importance of decision-making and advance planning and the risks and benefits associated with available treatment and care options.
- Develop and evaluate information guides and decision aids to provide seniors and their families with information to assist them in their decision-making.

Challenge 3:
To strengthen professional awareness.

Rationale:

Health care and social service providers do not systematically receive the education and training that is required to provide competent, comprehensive and compassionate care to seniors who are dying. This is true from a pre-service and continuing education perspective.

Recommendations:

- Develop educational programs in end-of-life care for seniors that are well grounded both theoretically and experientially.
- Systematically include in health care curricula issues related to death and dying generally and, more specifically, in later life.
- Provide health care and social service providers at all levels of training with concrete, insightful and culturally-sensitive education and training on end-of-life care for seniors.
- Prepare practitioners who can recognize the final phases of illnesses and understand and manage their own emotional reactions to death and dying.
- Guide curriculum development by best practice and emphasize respect for the values and preferences of seniors, communication skills, technical proficiency, an appreciation of cultural and spiritual diversity and an approach to care that is sensitive to the preferences, beliefs and values of seniors who are dying and their families.

Challenge 4:

To strengthen support for the provision of informal/family care.

Rationale:

The care of seniors who are dying is, in large measure, provided by families, in particular, wives and daughters. Families, however, are often not prepared for the level of arduousness and intensity of such care.

Recommendations:

- Include families as a focus of attention as initial decisions are made about treatment and care for seniors who are dying.
- Provide assistance to families as they try to understand, negotiate and co-ordinate the care that will be needed at home and in institutions of an acute and long-term nature.
- Train informal/family caregivers to be competent, skilled and confident in the care they are providing.
- Develop ways that families can share their experiences and hear about the experiences of other family caregivers.
- Develop a peer support network of informal caregivers where experienced caregivers are available in one-to-one or group situations to provide information and support to those who are currently providing informal care.
- Establish the position of "primary worker" who can assist with case management, co-ordinating other health care and social service providers and advocate for the senior and family.
- Strive for consistency of care among health care and social service providers.
- Develop strategies that allow for seniors who have no spouse to care for them to remain in their home should they so choose.
- Encourage the development of federal and provincial policies and programs that minimize the financial costs to seniors and their families of providing informal end-of-life care.
- Establish and evaluate follow-up services for family caregivers during the bereavement period to help them come to terms with the death of their loved one and make the necessary readjustments to their lives such as returning to work and re-establishing their social lives.

Challenge 5:

To ensure that end-of-life care for seniors is culturally and spiritually appropriate.

Rationale:

An increasingly diverse senior population will find comfort in end-of-life care that recognizes their cultural assumptions. Spiritual assumptions are also important. The last rites of the Catholic church, Islamic rituals around the time of death and the after-death and burial practices of the Jewish faith are but a few religious rituals that provide spiritual comfort for seniors and their families.

Recommendations:

- Ensure that seniors and their families are treated as unique individuals with particular beliefs, values and customs.
- Accommodate cultural preferences in whatever way possible.
- Involve non-traditional health team members such as interpreters, healers, counsellors and others as appropriate.
- Respect seniors' sense of privacy, modesty and dignity.
- Recognize the importance of spirituality in the lives of seniors.
- Increase the availability of pastoral care and chaplains in institutional settings.
- Encourage the use of strategies that support the finding of meaning in adversity.

Challenge 6:
To increase research attention to end-of-life care for seniors.

Rationale:

Dying in later life is a neglected area of research. Knowledge and understanding is currently inadequate to guide and support evidence-based treatment and care for seniors who are dying.

Recommendations:

- Develop methods and tools for evaluating quality of life and other outcomes of care for seniors who are dying.
- Determine where and how seniors die and the best ways of ensuring the delivery of competent, comprehensive and compassionate end-of-life care by families and health care and social service providers.
- Investigate how end-of-life care for seniors with intellectual impairment or dementia can best be provided.
- Continue to research the advantages and the challenges related to advance care directives with respect to end-of-life care for seniors.
- Increase the quantity and quality of research employing both quantitative and qualitative approaches to document the natural history of dying, and the influence of social support and stressful life events on morbidity and mortality in later life.
- Conduct research that furthers knowledge about the prevalence, clinical pathways and levels of distress and functional and cognitive impairment associated with pain and other symptoms including physical wasting, loss of appetite and weakness, shortness of breath and delirium, confusion and depression.
- Document the pathways taken by seniors through various settings and relationships, including home care, acute care and long-term care programs and providers and the outcomes of these pathways and relationships.
- Carry out studies about what it means to die in later life, both alone and in the company of others.
- Study the spiritual growth and other valued experiences of seniors who are dying.

Challenge 7:
To develop and evaluate model programs that reflect high quality end-of-life care for seniors.

Rationale:

Despite an increase in the number of textbooks, journals, fellowship programs, and academic and community-based clinical, education and research programs that focus on end-of-life care, there is little emphasis on the treatment and care of seniors who die from a multiplicity of diseases, many of which are chronic and progressive in nature.

Recommendations:

- Remove administrative, clinical, regulatory and reimbursement barriers to the systematic provision of high quality end-of-life care for seniors who are dying.
- Prevent the preclusion of seniors from end-of-life care of a supportive and palliative nature because of restrictive criteria for admission to programs and services, uncertain clinical trajectories and payment schedules that emphasize hospital services.
- Ensure that the philosophy and principles of palliative care are systematically employed in the care of seniors who are dying.
- Be sensitive to the cultural assumptions that are embedded in clinical programs and their relevance to a culturally diverse population of seniors.
- Develop strategies to reduce boundaries that prevent the access of seniors and their families to end-of-life care and that encourage rather than impede service delivery of an effective and palliative nature.
- Establish and evaluate model programs of a general nature that ensure that care for seniors who are dying is

based on best practice and that health care and social service providers in all settings are encouraged to employ effective and supportive strategies and are discouraged from employing those that are ineffective and/or harmful.

- Establish and evaluate model programs of a specialist nature to ensure that a cadre of experts are available to generalist providers in the solution of difficult physical, social and emotional problems that may be experienced by seniors who are dying and their families.

We, in Canada, have the resources to provide excellent end-of-life care for seniors. However, there are many steps that must be taken in the process of providing this care. This GUIDE is presented as part of that important process.