UBC Department
of Family Practice

CARE FOR ELDERS

Palliative Care

•Pre-reading •

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Palliative Care: (2004)

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Appendices (<u>not required prereading</u>):
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E. Do Not Resuscitate Form

Immediately following Appendices:

- **Case Study – Part I (first page only)**
- **Evaluation Form**

Welcome to the Care for Elders Modules!

The Care for Elders modules have been written for and by interdisciplinary teams. These modules are unique in that they are interactive and participatory. The goal is for you to learn about elders and also about you – exploring your role and attitudes; other disciplines; your team and how to work as part of a team caring for elders.

The Care for Elders learning experience is comprised of two parts:

1) Pre-reading - this is a general comprehensive overview of one topic
2) A 2 to 3 hour small group session with case study discussion.

- To get the most out of this module it is strongly recommended that you read the pre-reading package. Information in the pre-reading is reviewed during the small group discussions.
- Small groups will consist of 6-10 participants from various disciplines, and a facilitator.
- The facilitators will not 'teach'; rather your small group will discuss one fictional case using the information you possess, and the information you acquired from the pre-reading. The learning is accomplished if your team fully discusses the questions asked in the case study.
- The facilitator's role is to guide discussion and ensure that all learning points are covered during the session. Your facilitator is NOT expected to provide information!

We hope that this experience will be a rewarding one for you!

Palliative Care
Goals and Learning Objectives

At the end of the Palliative Care module, you will be able to:

1. describe how hospice palliative care/end of life care encompasses disease modification and symptom management within various disease trajectories,

2. describe the dimensions of whole person care,

3. demonstrate the significance of the family as the unit of care in hospice palliative care/end of life care,

4. identify unique characteristics of hospice palliative care/end of life care for elders,

5. incorporate the dimensions of diversity (culture, gender, race…) of clients (Stan and Betty) in hospice palliative care/end of life,

6. address issues of continuity, and transitions in providing hospice palliative care /end of life care across the continuum of care,

7. discuss the synergy and support provided by the interdisciplinary care approach to hospice palliative care/end of life care,

8. explore strategies for managing conflict within families and within the team,

9. create a patient/family centered care plan for Stan and Betty which addresses:
    - pain and symptom management
    - spirituality and existential issues
    - psychosocial issues
    - ethical and legal issues
    - quality of life
    - advance care planning
    - death management
    - grief, loss and bereavement,

10. identify skilful ways of delivering “bad news”,

11. reflect that hospice palliative care /end of life care can be very rewarding and emotionally challenging work for health professionals, and

12. identify how you will address your own self care needs.

1. Introduction

1.1 What do we mean by end-of-life care and hospice palliative care?

"End-of-life care" is the term used for the range of clinical and support services appropriate for dying patients and their families. It is the total care of people who are dying. It is active comfort care. The goal of end-of-life care is the same regardless of the setting—to ensure the best quality of life for dying patients and their families."

According to the Discussion Paper on a Provincial Strategy for End of Life Care in British Columbia, the term "end-of-life care" may also be used more broadly to include initiatives such as public education on advance care planning like Advance Directives.

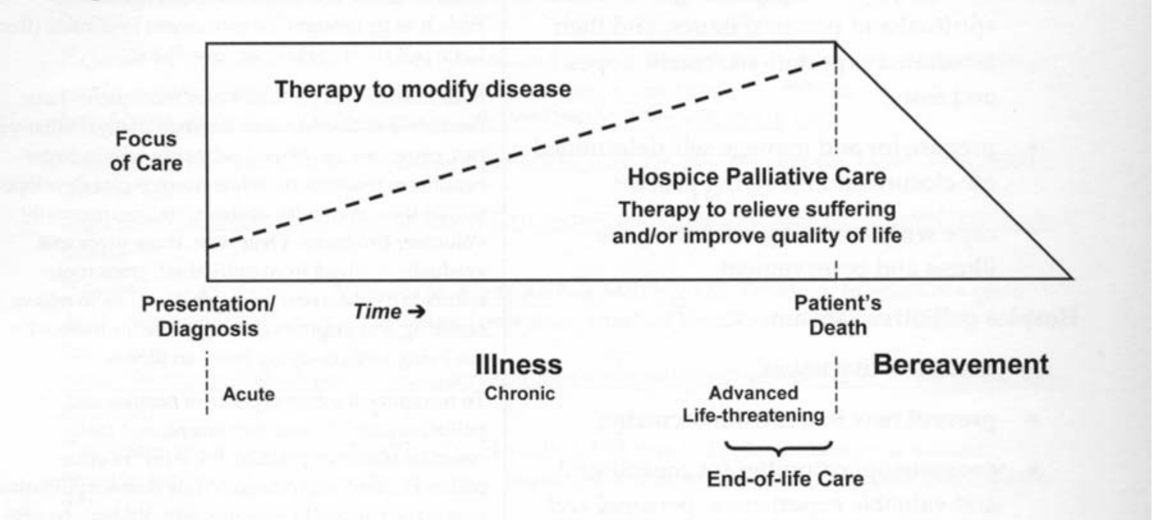
Hospice palliative care, based on the Canadian Hospice Palliative Care Association's *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* (www.chpca.net) "**aims to relieve suffering and improve the quality of living and dying.**
Hospice palliative care strives to help patients and families:

- **Address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears**
- **Prepare for and manage self-determined life closure and dying process**
- **Cope with loss and grief during the illness and bereavement"**

The goals for quality end-of-life care and hospice palliative care are the same. The term "end-of-life care" may be used to broaden the scope of care as hospice palliative care has been associated with the care of patients and families with life-threatening diseases, throughout their illness trajectory. Hospice palliative care may be associated with illnesses such as cancer, HIV-AIDS, and neurological conditions such as ALS. As some hospice palliative care programs may attach a prognosis such as three or six months to their program criteria, there may also be the belief that hospice palliative care and end-of-life care are limited to particular time periods. These perceived limitations related to diagnosis and prognosis are of concern when caring for elders with cardiovascular disease and dementia. Hospice palliative care and end-of-life care are applicable for these individuals as well.

The following diagram is helpful in understanding how hospice palliative care can fit within the individual's living and dying experience, regardless of diagnosis and prognosis. This diagram illustrates the relationship of therapies to modify the disease with therapies to relieve suffering and improve quality of life. In fact, in the context of hospice palliative care, criteria for the use of disease modifying therapies such as palliative chemotherapy or palliative radiation should be the impact on the individual's quality of life and symptom management rather than the prolongation of life.

Figure #8: The Role of Hospice Palliative Care During Illness

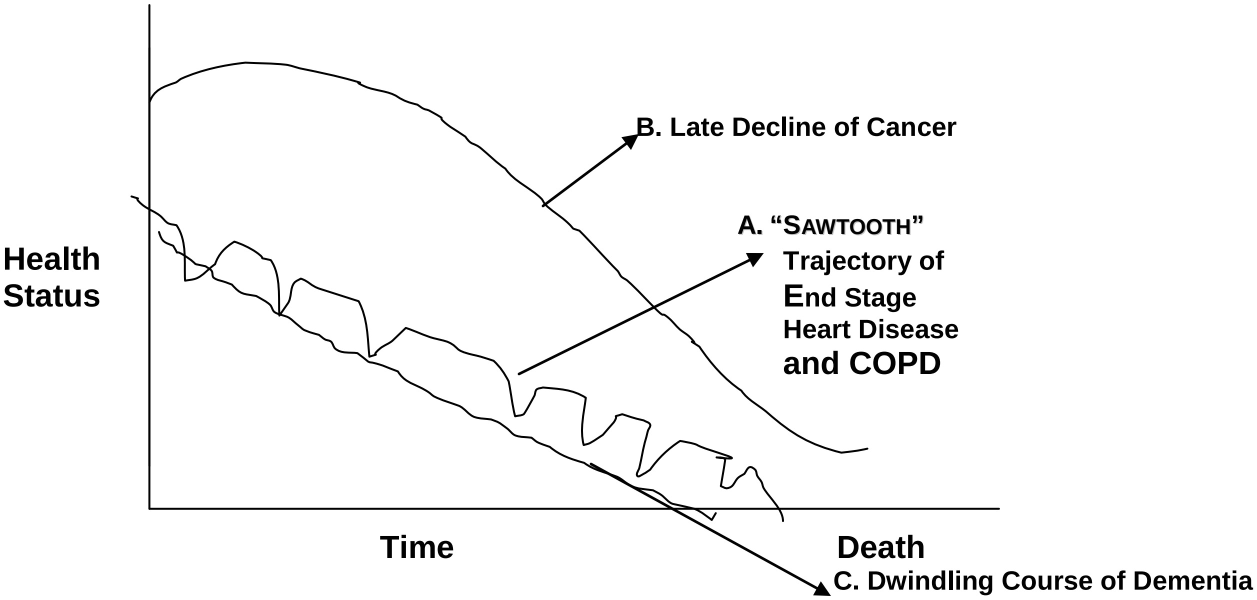


chpca—p.18

1.2 Illness Trajectory

In hospice palliative care, we often use the term “trajectory”. The term “disease trajectory” implies that specific diseases progress through their own relatively familiar courses including the pre morbid (early), symptomatic and end-of-life stages. Explaining what physical and functional changes may occur over blocks of time can also help clients and families to adjust their goals and expectations as the disease progresses.

Three Variations to End-of-Life Disease Trajectories



Source: www.camc.org/Institute/WVSHA/article1/.htm

a. “Sawtooth” trajectory of end stage heart disease and COPD

The first dying trajectory is familiar to clients living with chronic non-malignant diseases such as chronic obstructive pulmonary disease (COPD) and Congestive heart failure (CHF). CHF and COPD are common chronic illnesses. Diagnosis for both diseases is often made later in adult life and people often live with symptoms such as dyspnea, altered intake, nausea, pain, disturbed sleep, fatigue, anxiety, and changing elimination patterns for many, many years.

Individuals with CHF and COPD often experience a slow functional decline over many years accompanied by moments of crisis and periodic plateaus. Towards the end of life, the episodes of crisis become more frequent and death is often due to a “final” acute episode.

Unfortunately, end-of-life discussions regarding quality of life and how the next ‘crisis’ will be managed are often not done. However, experts in end-of-life care recommend these discussions be done when the physician believes that "it wouldn't be a surprise if this patient dies in the next six months". Following this type of discussion, the health care team and the client and family may be freer to take a "comfort only" approach to symptom management.

b. Late decline of cancer

The second end stage trajectory is that known to cancer patients. Cancer is a general term for abnormal cell growth. It occurs when normally dividing cells mutate, altering the normal gene structure and thus normal cell functioning. Cancer cells either have an accelerated rate of cell division or do not die at the end of their normal life span. As these dysfunctional cells accumulate, they can lump together to form a solid tumor, or spread throughout the body as a leukemia or lymphoma. The site where the cancer cells originally develop (e.g. lung cancer), is called the primary site and dictates the disease trajectory.

Primary cancers have a fairly predictable disease trajectory including patterns for metastatic disease (e.g.: bowel cancer often spreads to the liver). Initial symptoms vary depending upon the cancer location but pain, anorexia, weight loss and fatigue are common. As noted in the diagram, it is common that functional decline in individuals with a malignant disease is often seen toward the final months.

c. Dwindling course of dementia

Finally, persons living with dementia often experience a third variation of the dying trajectory. This is characterized by a very gradual functional and cognitive decline over many years. These persons usually slowly drift into a protracted bed ridden state requiring total care. End-of-life discussions often include balancing the patient’s quality of life with decisions to treat, or not treat, opportunistic infections and other complications.

Towards the end of life, families and clients often ask caregivers to predict when death will occur. An understanding of the variations in disease trajectory may help us to “map out” possible future expectations and anticipate decisions, but it does not provide us with the ability to predict the exact time when death will occur. At best, our role in hospice palliative care becomes that of supporting clients and families to live with uncertainty and to prepare for experiences in their own lives.

1.3 Hospice Palliative Care/End of Life Care for Seniors

One approaches care of older adults at this stage of their life in the same way as with other age groups- providing quality health care for the specific condition(s) with attention to symptom control and quality of life. There have been a number of studies that have defined the indicators of quality end of life care with significant overlap in the results. The study by Singer et al interviewed people with end-stage renal failure as well as people with end-stage HIV illness and the indicators of quality end of life care were:

- Receiving adequate pain and symptom management
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control
- Relieving burden
- Strengthening relationships.

Therefore, the approach to palliative care in the older adult would address these indicators of quality end of life care and would be the same as for other age groups. Unfortunately, there are myths and misconceptions of dying in later life that may compromise the ability to ensure quality end of life care and these would include:

- *Myth: Seniors don't need end of life care as they are going to die anyway*.
  - ➢ Fact: There are many issues that need to be addressed in this last phase of life for quality end of life care.
- *Myth: Most seniors die in long-term care facilities and therefore receive end of life care.*
  - ➢ Fact: Only 39% die in long-term care facilities and there is a need for education on many issues related to palliative care in that setting.
- *Myth: Seniors are completely prepared for death.*
  - ➢ Fact: There are issues such as indecision, ambivalence or denial affecting seniors and their families at this stage that need to be addressed.
- *Myth: Seniors die of "old age".*
  - ➢ Fact: Aging itself very rarely causes death. The leading causes of death amongst seniors are heart disease (31%), cancer (26%), respiratory diseases (11%) and strokes (9%).
- *Myth: There is nothing that can be done for seniors who are dying*
  - ➢ Fact: This module shows that there are many things that can and should be done to ensure quality end of life care.

Individualizing the care to a specific patient should then take into account conditions associated with aging. The general approach must be tailored for impairments that could include health areas (hearing, vision, cognition, multiple co-morbidities), function limitations and caregiver support challenges.

Specific considerations include:

1. Advanced <u>dementia</u> which is associated with a marked decrease in function and ability of the patient to participate in care decisions.

2. Extreme frailty whereby a patient may die with multiple chronic illnesses that have produced an accumulation of impairments with a fragile state leading to death and even where a small number of very old people die a 'natural death' with no significant underlying diseases evident.

2. Whole Person Care

By whole person care, we intend an approach to care that involves the total care of patients through the control of pain and other symptoms and attention to psychological, social, and spiritual problems. This approach to health care arose from the concern that an important phase in our journey as humans, the dying process, was being medicalized. The focus was on the treatment potentials for the illness, not the person's suffering, meaning and potential for life closure/personal growth. Hospice palliative care philosophy emphasizes caring for both the patient and family in a holistic manner.

2.1 The Family

Palliative care encompasses the concept of family centered care. Care of the family in palliative care frequently focuses on the differences in perception of the patient's experience of suffering and difficult symptoms and that of his or her family members. The significance of the family as the unit of care for the palliative care professional is often related to support in the task of caregiving which may cause excessive fatigue for family members. Family members may also experience conflicts in relation to caregiving and decision-making, general fears and concerns and unresolved bereavement issues. Family meetings are routinely held for the purposes of providing information, care planning to provide support to the family and assess the family's coping needs.

The palliative care professional needs to understand that:

1. The concept of the family encompasses a wide variety of definitions. e.g.: step family, homosexual family, the family as a friend.
2. The role of family caregivers in palliative care is vital in providing a nurturing environment for the patient.
3. There are both barriers and strengths to effective symptom management which may be influenced by the patient's family members. e.g.: fear of addiction to pain medication.
4. Family members may encounter ethical dilemmas in the care of a loved one e.g.: requests for euthanasia or physician-assisted suicide.
5. The family may express fear and general concern in the care of a loved one who is dying. e.g.: fear of causing further discomfort.
6. The family may require professional care and support in dealing with issues related to the care of a dying member. e.g.: referral to social worker or spiritual care.
7. The professional care provider may need to assess the function of communications between the patient and family. e.g.: conspiracy of silence, concerns about curative care vs. palliation.
8. The family may need special support in relation to loss and bereavement issues. e.g.: referral to a psychologist or bereavement counselor.

Dimensions of Whole Person Care

The dimensions of whole person care are illustrated in the following diagram from the Canadian Hospice Palliative Care Association's *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* (www.chpca.net) The issues commonly faced by patients and families are categorized into eight domains, each of equal importance. The diagram on the following page outlines these dimensions. The complexity of issues that individuals and their families face necessitates that hospice palliative care be provided by an interdisciplinary team as no one discipline can embody the knowledge and skills required to address all of these domains.

Dimensions of Whole Person

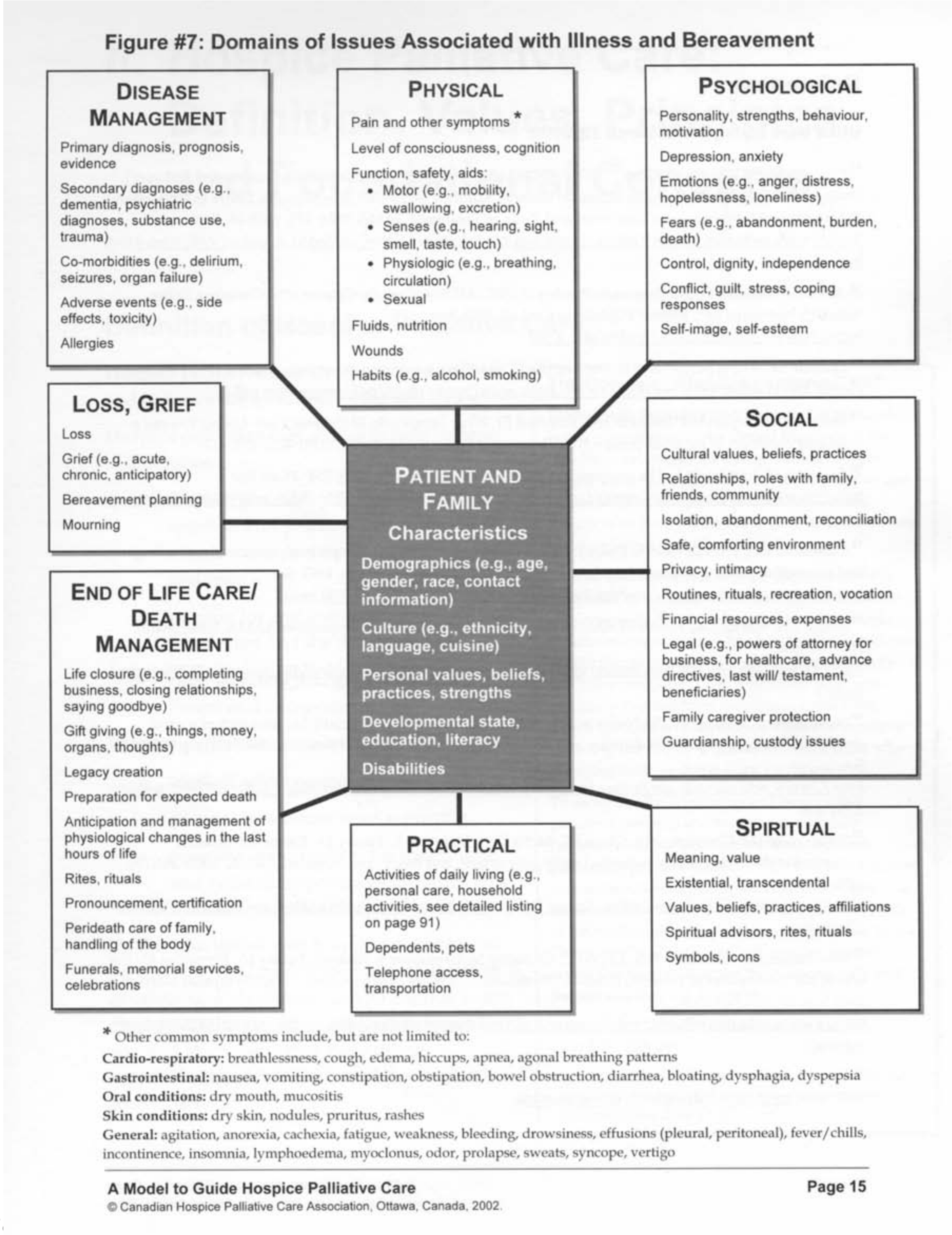


Figure #7: Domains of Issues Associated with Illness and Bereavement

DISEASE MANAGEMENT

Primary diagnosis, prognosis, evidence

Secondary diagnoses (e.g., dementia, psychiatric diagnoses, substance use, trauma)

Co-morbidities (e.g., delirium, seizures, organ failure)

Adverse events (e.g., side effects, toxicity)

Allergies

PHYSICAL

Pain and other symptoms *

Level of consciousness, cognition

Function, safety, aids:
- Motor (e.g., mobility, swallowing, excretion)
- Senses (e.g., hearing, sight, smell, taste, touch)
- Physiologic (e.g., breathing, circulation)
- Sexual

Fluids, nutrition

Wounds

Habits (e.g., alcohol, smoking)

PSYCHOLOGICAL

Personality, strengths, behaviour, motivation

Depression, anxiety

Emotions (e.g., anger, distress, hopelessness, loneliness)

Fears (e.g., abandonment, burden, death)

Control, dignity, independence

Conflict, guilt, stress, coping responses

Self-image, self-esteem

LOSS, GRIEF

Loss

Grief (e.g., acute, chronic, anticipatory)

Bereavement planning

Mourning

PATIENT AND FAMILY

Characteristics

Demographics (e.g., age, gender, race, contact information)

Culture (e.g., ethnicity, language, cuisine)

Personal values, beliefs, practices, strengths

Developmental state, education, literacy

Disabilities

SOCIAL

Cultural values, beliefs, practices

Relationships, roles with family, friends, community

Isolation, abandonment, reconciliation

Safe, comforting environment

Privacy, intimacy

Routines, rituals, recreation, vocation

Financial resources, expenses

Legal (e.g., powers of attorney for business, for healthcare, advance directives, last will/ testament, beneficiaries)

Family caregiver protection

Guardianship, custody issues

END OF LIFE CARE/ DEATH MANAGEMENT

Life closure (e.g., completing business, closing relationships, saying goodbye)

Gift giving (e.g., things, money, organs, thoughts)

Legacy creation

Preparation for expected death

Anticipation and management of physiological changes in the last hours of life

Rites, rituals

Pronouncement, certification

Perideath care of family, handling of the body

Funerals, memorial services, celebrations

PRACTICAL

Activities of daily living (e.g., personal care, household activities, see detailed listing on page 91)

Dependents, pets

Telephone access, transportation

SPIRITUAL

Meaning, value

Existential, transcendental

Values, beliefs, practices, affiliations

Spiritual advisors, rites, rituals

Symbols, icons

* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

A Model to Guide Hospice Palliative Care **Page 15**

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The following sections provide information relating to various dimensions of whole person care.

2.2.1 Pain and symptom management

Approaching symptom management for palliative care for elders requires a melding of the approaches to symptom management for geriatrics and palliative care. There are differences in the frequency of symptoms experienced by patients with progressive illnesses other than cancer and patients with cancer. Pain, dyspnea, confusion/delirium, anorexia and depression are common to all with advanced illness, however, nausea/vomiting and constipation occur more frequently in those with cancer.

As symptoms are subjective, the patient is the primary source of information. Self-report of symptoms can be impeded by: reluctance to be seen as a complainer, fears of the meaning of the symptom, or fears of the suggested treatments. Patients may describe symptoms using other words such as pain described as discomfort or heaviness. It is important to assess symptoms at regular intervals. For cognitively impaired elders, observations from family and care providers are especially important.

Symptom assessment consists of the following:

- Identification of the cause of the symptom
- Measurement of the quality and intensity of the symptom
- Recognition of the multi-dimensional aspect of the symptom, i.e. how it is affecting the person’s function, psychological state, and social/cultural/spiritual experience

Medications are often the mainstay of symptom management and the approaches for palliative care in the elderly are the same as for other palliative care patients. However, given that elders often have more medical conditions than younger adults, the risks of medication-related side effects are greater. As elimination of medications by the kidney and liver is affected by aging, elders may be more sensitive to the central nervous system effects of some medications. The possibility of adverse drug effects is greater. The following principles for medication use with elders apply to palliative care:

- Know the person: the person’s illness, current medications including over-the-counter and complementary medication, and medication history
- Establish treatment goals and review them regularly to assess response. For example, in treating severe pain, the goal of pain relief may be divided into three steps: achieving a pain-free night’s rest, achieving no pain at rest, and finally achieving no pain upon movement. Other symptoms can be divided into similar goals.
- Know the drugs. In general, start with low doses and titrate upwards. Minimize the number of medications, avoid duplication, and simplify the dosing regimen as much as possible. As with other patients, oral routes are usually preferable and “round-the-clock” dosing should be initiated with any medication required to control a “constant” symptom. The step-wise World Health Organization system for pain management is a good approach. Sustained release medications such as opioids can be helpful in simplifying the regimen, but only after careful

titration with a short-acting opioid to determine the appropriate dose. Similarly, short-acting benzodiazepines (lorazepam or oxazepam) are preferable to long-acting when used with elderly patients. Dilaudid or hydromorphone is often preferred over morphine for use with the elderly. Explore the person's fears and beliefs about the medication--elders can be particularly concerned about addiction, that medication will hasten death, or that medication needs to be "saved" for use with more intense pain later in the illness.

2.2.2 Psychosocial Dimension

Quality of Life

Quality of life can be defined as the individual's sense of well-being. It is the essence of living while dying. Quality of life relates both to experiences that are meaningful and valuable to the individual and his/her capacity to have such experiences. As quality of life is completely subjective, we can never judge another person's quality of life.

Quality of life in the face of illness is the result of the interaction between illness, health care, and the individual's life experience to date. It can often reflect the difference between a person's current expectations of life and current experience. Thus, those persons living and dying of an illness can achieve good quality of life.

Coping with dying

Patients and families cope with their illness and dying experience as they have coped with other stresses in their lives—it is commonly acknowledged in palliative care that "we die as we live". Typically, the following issues create distress for dying patients:

- concerns about comfort—worries about pain, fatigue, loss of appetite, confusion, breathing problems, constipation, nausea and other symptoms
- problems in performing one's normal activities such as social or household activities, maintaining relationships with family and friends, personal care routines, and activities of daily life (eating, sleeping, mobility and communication etc.)
- fears about dying, for example, suffering and abandonment

Sadness, Depression and Demoralization

One question that arises in the care of persons at end-of-life is differentiating between depression and normal sadness as the person deals with the losses involved with progressive illness. Many of the signs of depression in a healthy population, such as loss of appetite, fatigue, difficulty sleeping and poor concentration, may be related to the illness itself. Feeling sad at times is appropriate. More reliable symptoms for the diagnosis of depression are fearfulness, social withdrawal, brooding, self-pity, pessimism, a sense of punishment or a mood that cannot be changed (never smiles or responds to good news). Depression and anxiety in persons at end-of-life are thought to be under-diagnosed, which can increase suffering and further decrease quality of life. Depression and anxiety can be treated using the same pharmacological agents as are usually used, plus supportive therapy and referral for psychiatric intervention if the depression and anxiety do not respond to treatment.

More recently, there is recognition of the demoralization syndrome occurring in those with terminal illness. Demoralization is differentiated from depression in that the demoralized person has the capacity to experience immediate pleasure or happiness but resembles the depressed person in hopelessness, helplessness, loss of purpose or motivation and existential distress. Demoralization responds to a supportive spiritual and/or existential approach. The focus of therapy is on the promotion of hope, finding meaning and a sense of connectedness, through the involvement of family, friends, and the interdisciplinary team.

2.2.3 Spiritual and Existential Dimension

Spirituality which involves the person's personal, interpersonal, religious/spiritual values and beliefs is an integral aspect of caring for the whole person in palliative care. The process of inner healing involves the person's journey towards integration and wholeness. It may or may not involve physical healing. The degree to which a person is able to find inner strength in the event of terminal illness may depend on how or whether the person is able to reframe his or her situation to allow for a process of inner healing. Pain, loss, illness, grief or death are fundamental features of our existence that which may allow for reflection on existential concerns or questions surrounding personal meaning. Suffering and pain may be perceived by some people as transformative in that it allows the person to connect with something in his or her life that is deeply felt or which has meaning and purpose. For example, recent studies on existential and spiritual suffering in patients who are terminally ill reveal that suffering is transformed through finding meaning in illness and a sense of connectedness with self, others, nature or 'The Other'.

The palliative care provider should know the importance of seeking appropriate help in responding to the spiritual needs and questions of the patient. eg: fears related to spiritual beliefs. It is important to recognize that the patient's spiritual and cultural beliefs as well as language are integral aspects of palliative care. It is also important to recognize the effect of the beliefs of the patient and his/her family members and care providers on the process of care.

2.2.4 Ethical Issues

"Ethical issues in palliative care center around decisions which enable us to satisfy the criteria for a peaceful death, dignified and assisted by a helpful society." The principal ethical issues are categorized in the following table:

Table 1: Principal Palliative Care Ethical Issues*

Issue	**"How do we ensure" :**
Competence	Access to clinically competent health professionals
Communication with health professionals	Patients/families have access to information for decision-making
Confidentiality	Confidentiality in exchanging sensitive information within the expanded "team"

Issue	**"How do we ensure" :**
Cultural sensitivity	Respect cultures, yet maintain a consistent ethical approach, e.g. truth-telling about the diagnosis where in some cultures the patient is not told the diagnosis
Dual ethical standards	Rationalize promotion of legal products such as cigarettes when we wouldn't ethically accept promoting ill health for personal gain
Education of health professionals	Ensure that our educational system recognizes and reflects the view that the principles of palliative care are essential components of healthcare provider practice
Euthanasia and physician-assisted suicide	As a society, deal with highly valued autonomy and consider legalization, especially while ensuring that patients have impeccable access to excellent palliative care
Life-prolonging therapy	Balance the relative benefit to a few people of aggressive therapies that may have high risk and low benefit? Support nurses and other health professionals who have to deliver these therapies but don't have the authority to decide to proceed or not
Research	Studies are ethical in fragile populations if patients are competent to consent, there is no conflict of interest, and ineligibility doesn't affect their medical care options
Responsibilities of health professionals	Health professionals are supported to balance their responsibilities to their patients/families, institutions, society at large and their own personal life/families in our complex society
Resource allocation	Resource allocation decisions reflect the increasing numbers of patients needing palliative care, not by reducing the options for care- e.g. if hospital beds are reduced, is there a balancing increase in home support and hospice services?
Standards of care	Health services demonstrate that they maintain an acceptable standard of care and competence
Withholding or withdrawing therapy	Decisions to continue with or not start therapies that may be futile in patients with poor quality of life are made with full understanding and not driven by personal agenda or the health or legal systems, thereby causing added suffering for patients and costs for society
Unorthodox therapies	There is a balance of support for autonomy of

Issue	**"How do we ensure" :**
	decisions to seek these therapies, adequate information for decision-making and protection from harmful therapies and exploitation.

***From: Roy, DJ, MacDonald <u>Oxford Textbook of Palliative Medicine</u> 1998, p98**

For health care professionals, ethical issues in clinical practice ("clinical ethics") arise when the answers proposed to any given question are uncertain or conflicting: e.g. what should or should not be done, clinical acts that may be tolerable, if not ideal, in the care of people with advanced or terminal disease. Since there may be values and beliefs in conflict and since it is necessary to recognize this situation and have ways of moving forward to provide quality care in a consensual team environment, it is necessary to have a way in clinical practice to frame and deal with these ethical issues and dilemmas. Such practice frameworks have been developed and are used in many palliative care settings; all health professionals should avail themselves of such supports. One such framework is available through Vancouver Community Health Services and is attached as an appendix (The Risk Assessment Approach and The Ethics Framework).

2.2.5 End of Life Care/Death Management

Advance Care Planning

There are many decisions that may need to be made by the patient/family related to quality palliative care. Furthermore, it is now recognized that issues at the end of life can benefit from anticipatory planning well before that stage is reached and this is increasingly being promoted as advance care planning. One common area of advance care planning is making one's values and goals for a quality end-of-life explicit to oneself, the family and the health care professionals through advance directives. Advance directives relate to future care decisions such as health care, personal care, living arrangements and financial arrangements. Legal avenues in British Columbia include the Representation Agreement for health and financial matters and a Power of Attorney for financial matters. Information on the various areas of advance care planning and the legal avenues in B.C. is available on the website of the Public Guardian and trustee of BC at: www.trustee.bc.ca.

As the illness advances, care planning may include issues such as whether people wish to remain at home for their death or go to hospital/hospice, funeral planning, and organ donation. Based on the issues that have been experienced thus far with the illness or are likely to occur with the illness, discussions around patients' treatment wishes can occur. For example, discussions related to further chemotherapy, the use of antibiotics to treat a pneumonia, or the desire to continue with transfusions and other medical treatments, can be explored; always with the reassurance that comfort will be maintained. Some people can make decisions in advance; others may need to be in the circumstance, with what they consider to be poor quality of life, before they can contemplate letting go of treatment options.

End of Life Closure

Persons vary greatly as to when they begin to prepare for death. Some people begin preparations even before knowledge of a terminal diagnosis, by preparing a will or advance directive. Others, although very ill, may never acknowledge that they are dying. However, most persons find that they can have quality living in their final days and also attend to intrapersonal and interpersonal needs related to the end of life.

The ‘landmarks and tasks’ that many dying individuals experience were identified by Dr. Ira Byock (1996). While they cannot be considered representative of every dying person’s experience, they do provide a useful framework for understanding the journey of many dying individuals.

<u>Byock’s Developmental Landmarks and Tasks at the End of Life</u>

Sense of completion with worldly affairs
- Transfer of fiscal, legal and formal social responsibilities; this can take the form of a Will, Power of Attorney or other practical matters

Sense of completion in relationships with community
- Closure of multiple relationships (employment, commerce, organizational, congregational). Components include: expressions of regret, expressions of forgiveness, acceptance of gratitude and appreciation; saying good-bye

Sense of meaning about one’s’ individual life
- Life review; the telling of “one’s stories”; some people enjoy making an audio-tape, organizing photo albums, or a CD of their favorite songs

Experience love of self
- Self-acknowledgment; self-forgiveness

Experience love of others
- Acceptance of worthiness; able to accept care from others without undue concern of being a burden

Sense of completion in relationships with family and friends
- Reconciliation and closure in one’s important relationships. Component tasks include: expressions of regret, expressions of forgiveness and acceptance, expressions of gratitude and appreciation, acceptance of gratitude and appreciation, expressions of affection
- Leave taking; the saying of good-bye; planning of significant gifts to be given in the future; participation in planning one’s funeral

Acceptance of the finality of life - of one’s existence as an individual
- Acknowledgment of the totality of personal loss represented by one’s dying and
- experience of personal pain of existential loss
- Expression of the depth of personal tragedy that dying represents
- Decathexis (emotional withdrawal) from worldly affairs and cathexis (emotional connection) with an enduring construct
- Acceptance of dependency

Sense of a new self (personhood) beyond personal loss

Sense of meaning about life in general
- Achieving a sense of awe; recognition of a transcendent realm
- Developing/achieving a sense of comfort with chaos

Surrender to the transcendent, to the unknown - “letting go”

Imminent Death

The dying process varies depending on the person and the illness, but there are some predictable physical, physiologic and emotional changes that occur during the final days and hours of life. Knowing what to expect is helpful for care providers to prepare patients and families. Signs of impending death include: drawing inward, end-of-life experiences such as visits from family members who have died, reduced energy to the extent of being bed-bound, intake decreased to tastes and sips only, and sleeping most of the time. These last days and hours can be the significant time of our lives providing last opportunities to:

- finish our business
- create final memories
- give final gifts
- achieve spiritual peace
- say good-bye

Table 2 summarizes the common physical signs of approaching death.

Table 2: Physical Signs of Approaching Death

- Reduced level of responsiveness
- Restlessness and disorientation
- Taking no fluids or only sips
- No urine output or small amount of very dark urine (anuria or olgiuria); incontinence of stool
- Progressing coldness and purple discoloration in legs and arms
- Laborious breathing; periods of no breath for 5-30 seconds (Cheyne-Stokes breathing)
- Bubbling sound in throat and chest (respiratory congestion, previously termed “death rattle”)

Clinician Checklist for Actively Dying Patients—adapted from Hallenbeck (2003)

The following comments provide guidance for care in the last day(s) of life.

- Establish and maintain a peaceful and comfortable environment—this includes attention to coverings for the patient, lighting, temperature, sounds (music as well as familiar voices), smells etc. The environment should be adjusted based on what is known about the patient’s preferences and observations of what promotes comfort.

- Notify and educate the family about the possibility/probability of the impending death. The importance of the family cannot be over-stressed. Everything that happens in the last hours of life will be remembered by the family. It is important to address the families’ previous experiences with death, fears and expectations, and reassure that dying is a natural process. Encourage the family to spend time with the patient, to continue to provide care as much as desired, and explain to them the changes that occur as the person dies. Conversation should not be hushed and children should be encouraged to visit if they wish. Laughter and tears are part of celebrating a loved one's life. Encourage the family to give their loved one permission to let go, not to try to hold on to life. If someone is alone, it may be helpful to ask them if there is a friend or relative who could companion them and help at the time of death.

- Review medications and other therapeutic interventions in light of the changes in the person's status. Are all medications still necessary? Medications for symptom control are continued but the route will need to be changed as swallowing is no longer reliable. Analgesics, antiemetics, anxiolytics/sedatives, and anticonvulsants are commonly given. If previously given regularly, medications are continued regularly. A low dose of opioid may need to be added or the regular dose increased by 25 % for pain or dyspnea. If the patient is anxious add an anxiolytic, often subcutaneous (sc) ativan or nozinan. If delirious, treat as delirium with neuroleptic medications.

- In addition to opioids and anxiolytics for shortness of breath, consider providing oxygen by nasal prongs, using a gentle fan, or fresh air breeze. Oxygen saturations should not be taken—patient comfort is the guide for actions and titration of the medications. If respiratory secretions are troublesome, scopolamine sc can be used to help dry secretions. The term "respiratory congestion" is now being used rather than "death rattle" to describe the secretions. If hydration via IV or PEG tube is being given, it is often helpful to discuss discontinuation to help reduce respiratory secretions.

- Mouth care is very important—keep the mouth moist with water and artificial saliva products. Families can often help with this. Families can be assured that IV/sc hydration does not contribute to comfort at this stage (in fact, may increase respiratory secretions, voiding, gastric secretions etc) and that dry mouth occurs with or without hydration.

- If the patient is dying at home, it is important to review that the family should not call the Emergency number, 911, at the time of death. A written care plan should be present to help the family know how to address symptoms and whom to contact for assistance as well as at the time of death. An institutional backup should be discussed with the family; a Do Not Resuscitate form should be present in case transfer to hospice/hospital is required. Additional caregiving supports for the family should be considered to prevent caregiver exhaustion.

Death

Irreversible failure of body systems leads to death but the cause of death is always cardiopulmonary failure. Death occurs when the heart or the lungs fail to perfuse and oxygenate vital tissues. Circulatory failure or pulmonary failure precedes death. Table 3 describes the signs of death.

Table 3: Signs of Death

- ➢ Cessation of heart beat and respiration
- ➢ Pupils fixed and dilated

- The person cannot be aroused; no response to stimuli
- Eyelids open without blinking; eyes are in a fixed stare
- Initially the body may be warm; decreasing body temperature
- Jaw relaxed and mouth may fall open
- Body color is waxen pallor

After Death

Whether at home or in the hospital, there is a tendency to “hurry through” after the person dies. It should be understood by all that there is no reason to hurry. Slowing the after-death events allows the family more time to begin to understand the reality of what has just happened and to say goodbye. Some families may wish to sit with the body, while others wish not to. Families can be informed that they can touch or hold the body if they so wish.

Practical issues will need to be addressed:

- Pronouncement of the death can be done by a physician, nurse or any delegate who can recognize the signs of death.
- A physician needs to complete a medical certificate of death. This certificate is necessary to obtain a death certificate from Vital Statistics as well as for funeral arrangements.
- Contact with the family’s spiritual advisor may be desired.
- Contact the executor of the will, if the person had a will. There may be funeral instructions in the will.
- A funeral home needs to be contacted—it is helpful if the funeral plan is in place prior to death.
- Communicating the death to those who need to know, either by newspaper, phone or letter—develop a plan as to who can help with this.
- Contact insurance companies to cancel insurance (eg automobile insurance) for refund of unused premiums. Also contact credit card companies, banks, Motor Vehicle Branch, Medical Services Plan etc to cancel services.
- Check carefully for all life insurance including Canada Pension, Veteran Affairs, Trade or credit union plans etc. Debts such as mortgages and installment purchases may have insurance clauses that will pay the balance of the debt.

Many institutions or palliative care programs have helpful booklets for families concerning both impending death and what to do following a death.

2.2.6 Grief, Loss & Bereavement

Many people suffer without relief when they are unable to understand the process of grieving and when they and those around them are unable to find any place of healing within their loss. Some people may suffer with unresolved grief for years and any subsequent losses accumulate and are added to the person's continuing grief. Unresolved grief may require referral to a mental health specialist. Some of the difficulties in attempting to understand the process of bereavement may stem from cultural beliefs embedded within contemporary society that death and dying are unnatural and abnormal which may lead to uninformed assumptions about death and dying. Bereavement refers to the emotional state of being bereft which means to be 'torn' apart. The nature of the grief process may vary from the sudden death of a close and deeply loved one, to the death of someone to whom there is not such a deep connection. Whether the bereavement is for the loss of someone close such as a lifelong partner or spouse or for a distant acquaintance, any form of grief is valid. When the person who died was intimately connected to the grieving person and that person's daily life, then the sadness may be more intense and prolonged.

The nature of grief may manifest itself physically as well as emotionally. Physical symptoms can be frightening and unsettling although they are inevitably temporary. Some of these symptoms may include shortness of breath, insomnia or loss of appetite. Physical symptoms should always be assessed clinically.

Bereavement may be experienced over time in cyclical phases which resemble numbness, shock, denial, guilt, disbelief, anger, intense sadness, full awareness and varying levels of healing. People eventually find that they are able to cope with the tasks and functions of everyday life and to find some measure of inner healing. However, being able to continue on with one's life, does not necessarily mean that the grief is over or that the love and the memories of the loved person have ended. It is more likely to mean that that person is managing to cope with life and to find a way through the process of mourning to a place of healing. Bereavement counseling may extend beyond the person's involvement with the palliative care team.

3.0 Delivering hospice palliative care

3.1 The Interdisciplinary Team: “Think Team”

Palliative care places a central focus on the roles and functioning of the interdisciplinary team. The role of each individual member is considered of equal importance in enabling the practice of total care of the patient and family. The overall goal of the team is the quality of life of the patient and his or her family. Therefore, importance is placed on: learning about effective team development; the challenges to team functioning; potential problems within interdisciplinary teamwork; conflict management and stress; and support .within the interdisciplinary team.

3.2 Care Process for an Individual and Family

The process for providing hospice palliative care can be conceptualized as six essential and basic steps that guide the interaction between the interdisciplinary team, the person and their family.

The following figure describes these steps.

Essential and Basic Steps During a Therapeutic Encounter

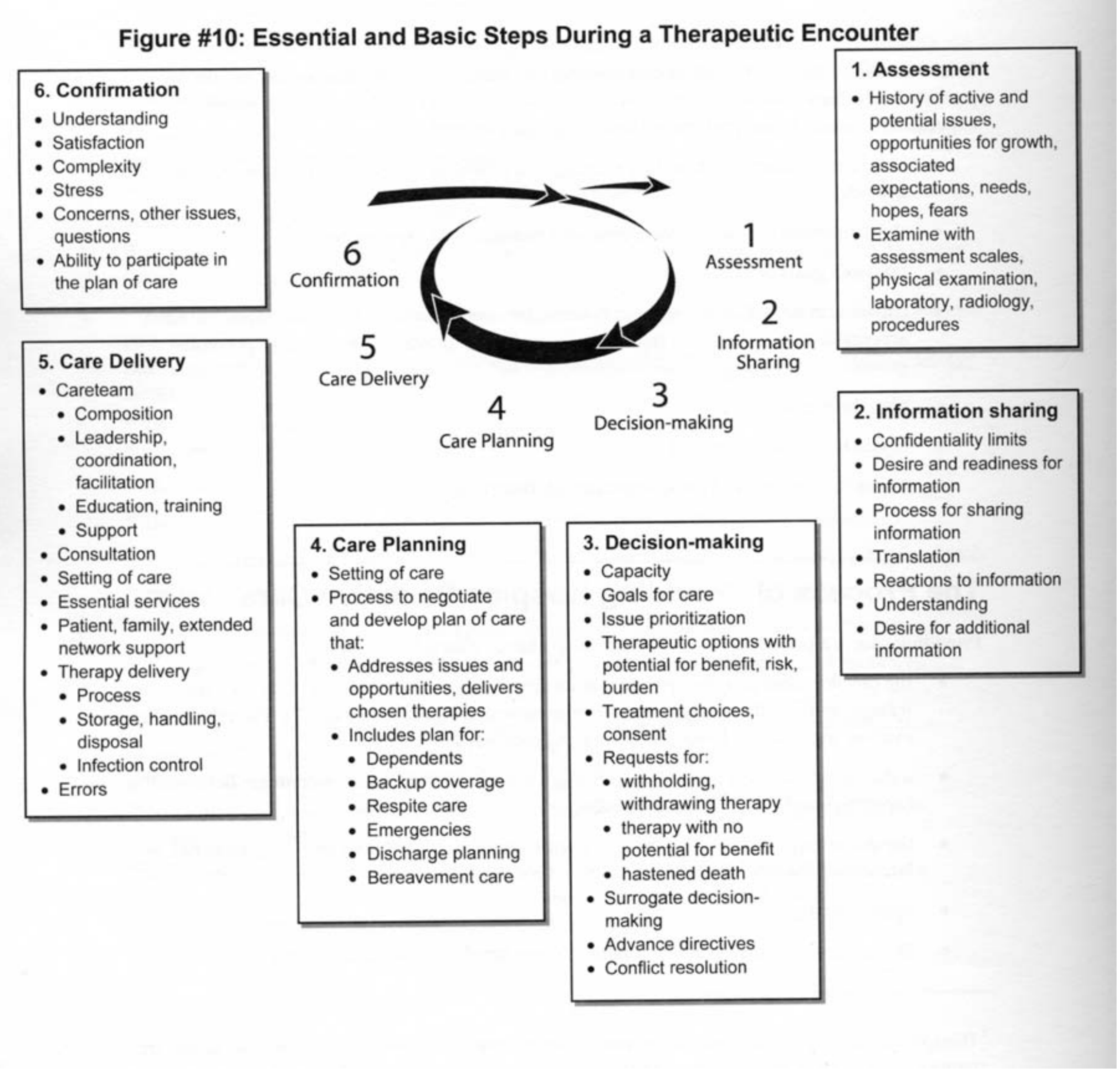

Figure #10: Essential and Basic Steps During a Therapeutic Encounter

1. Assessment
- History of active and potential issues, opportunities for growth, associated expectations, needs, hopes, fears
- Examine with assessment scales, physical examination, laboratory, radiology, procedures

2. Information sharing
- Confidentiality limits
- Desire and readiness for information
- Process for sharing information
- Translation
- Reactions to information
- Understanding
- Desire for additional information

3. Decision-making
- Capacity
- Goals for care
- Issue prioritization
- Therapeutic options with potential for benefit, risk, burden
- Treatment choices, consent
- Requests for:
  - withholding, withdrawing therapy
  - therapy with no potential for benefit
  - hastened death
- Surrogate decision-making
- Advance directives
- Conflict resolution

4. Care Planning
- Setting of care
- Process to negotiate and develop plan of care that:
  - Addresses issues and opportunities, delivers chosen therapies
  - Includes plan for:
    - Dependents
    - Backup coverage
    - Respite care
    - Emergencies
    - Discharge planning
    - Bereavement care

5. Care Delivery
- Careteam
  - Composition
  - Leadership, coordination, facilitation
  - Education, training
  - Support
- Consultation
- Setting of care
- Essential services
- Patient, family, extended network support
- Therapy delivery
  - Process
  - Storage, handling, disposal
  - Infection control
- Errors

6. Confirmation
- Understanding
- Satisfaction
- Complexity
- Stress
- Concerns, other issues, questions
- Ability to participate in the plan of care

3.3 Managing Conflict within Families and Team

Effective communication in palliative care requires excellent listening skills and an empathetic and supportive dialogue between patient, family and team members.

<u>Patient and Family</u>
Effective conflict management requires:
1. active listening,
2. recognition of the potential for varying emotions in patients and family, and their interactions eg: anger, guilt, fear and

3. the need to handle conflict in family and patient communications constructively.

The Team

Effective conflict management requires:
1. active listening,
2. recognition of the inevitability of conflict,
3. recognition of professional rivalries and boundaries,
4. the need to handle conflict in team communications constructively, and
5. recognition that the skills and contributions of others, both medical and non-medical, contribute to teamwork in palliative care.

3.4 Skillful Ways of Breaking Bad News

Breaking bad news can be a personally difficult communication for the palliative care provider. There are, however, compassionate ways of conveying bad news which ensure accuracy of information, constructive care planning and which allow the patient and his or her family to maintain a realistic sense of hope.

Six Step Protocol for Breaking Bad News
1. Attention to the physical context, e.g.: the room layout is private and comfortable.
2. Assessment of the patient's current emotional state, e.g.: is the patient visibly frightened, anxious, distraught or angry?
3. Assessment of the style and content of the patient's verbal and non-verbal responses, e.g.: does the patient respond through silence, disbelief, sadness or anger?
4. Recognition of the need to use clear, understandable language in a sensitive manner, e.g.: I'm afraid the tumour on your lung has spread more than we had hoped.
5. Assessment of the patient's coping strategies and needs for support, e.g.: presence of family members, spiritual support, information seeking support.
6. Planning future care within realistic expectations and maintain hope, e.g.: desire to see a grandchild, desire to travel.

3.5 Providing Hospice Palliative Care/End-of-Life Care as a "System" of Care

Most hospice palliative care systems are built on the assumption that primary health care providers, like Family Physicians and Home Care Nurses, can provide the basic care, with support provided by specialists as necessary. Specialist services are normally only needed near the end of life by a small proportion of persons and their significant family members or friends. When specialist services are needed, they are only needed for a proportion of the person's illness experience.

The essential components for an integrated system of end-of-life services are:
- Care coordination—often this role is played by a Home Care Nurse working in conjunction with a Family Physician

- Provision of equipment and medication in the home. In British Columbia, individuals are eligible for the Palliative Care Benefit Program, which covers selected medications and equipment in the home or care facility, if the treatment approach is palliative rather than curative and their prognosis is six months or less (Appendix C)
- Support for family and friends as caregivers—this includes practical, emotional and financial support. The new federal Compassionate Leave Program allows family caregivers to share up to six weeks of Unemployment Insurance benefits to care for a loved one—see attached brochure in Appendix D
- Respite for caregivers in the home, using Home Support workers and Hospice volunteers; and out-of-the home, such as in a hospice, long-term care setting or a hospital. This respite should be available on a planned and Emergency basis.
- Access to hospice palliative care specialists for emergency consultation. In B.C., there is a 24 hr/ 7 days a week toll-free number for health professionals to call to obtain advice from hospice palliative care physician experts--# 1-877-711-5757
- Specialized settings for pain and symptom management as well as settings which can provide end-of-life comfort care.

Transitions in Care

The care systems for hospice palliative care and end-of-life care need to address transitions between care providers working in different settings. Communication tools which document decisions made by individuals and their families are important. Examples of these communication tools are No Cardiopulmonary Resuscitation orders (see Appendix E) and Advance Directives.

3.6 The Rewards of Working with Palliative Patients and Families

As well as the rewards of participating in an effective interdisciplinary team, care providers may find the experience of caring for the dying both meaningful and transforming. Palliative care makes it possible to cross the boundary of ‘detached’ clinician and to work in a closer state of relatedness. However, since care providers may need to respond to fears of dying and existential suffering in patients, this may elicit emotional responses within themselves. It is important for care providers to understand these complex processes related to patients’ concerns and their own responses to these concerns. It may be necessary for the care provider to seek out emotional support from within the team as well as from external resources such as self-help groups or individual counseling.

3.7 Care for the Caregivers

There are other forms of personal and organizational stressors in palliative care which involve system constraints, for example, inadequate staffing and financial constraints as well as ethical and legal issues. In all of these issues, whether they are externally related or perceived as being internal, it is important for the palliative care provider to be aware of the need for his or her own self-care. Personal self-care entails finding differing ways of coping with stress and personal anxiety e.g.: recognizing internal stress and fatigue; identifying the source of anxiety; taking time off for one’s family, and other activities.

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Appendices

(Not required for Pre-reading)

draft

APPENDIX A
RISK ASSESSMENT AND CARE PLANNING TOOL

I. Purpose

The purpose of the risk assessment tool is to promote collaboration between clients, caregivers, and health professionals in identifying client strengths, areas of risk and the resources that are available (currently or potentially) to provide safe care in their home environment. This information should provide the basis for realistic goal setting and care planning.

II. Considerations

1. Consultation between client, caregivers and health care professionals is an essential part of risk assessment. The caregiver may be a spouse, family member or significant other. *If consensus is not reached about client risk this should be identified.*
2. Individual risk factors may be tolerable. When there are several risk factors the client's overall risk may become intolerable.
3. Client goals and strengths, the identified risks and resources currently in use or potentially available should provide direction for the development of the care plan.
4. Levels of risk are assessed as follows:

There are three levels of risk:

0	No risk- no intervention required.
1	Tolerable risk-intervention may or may not be required.
2	Intolerable risk-intervention required.

Intolerable risk has six elements:

- A change in the person that impairs his or her ability to protect himself/herself or others, from harm
- Evidence of current decline/severe change in condition
- The severity of the anticipated harm
- The high probability that decline/severe change will occur
- The imposition of risks on others
- The inability to choose to run a risk

(adapted from original risk appraisal work by Geriatric Clinical Practice Working Group, April 1997)

CLIENT RISK ASSESSMENT TOOL

Name:	**Age:**				
Continuing Care #:	**Goals of Care:**	**0**	**No Risk**	**Cl**	**Client**
Level of Care (if known)	☐ **Acute/Curative**	**1**	**Tolerable Risk**	**CG**	**Care Giver**
A/OA Staff	☐ **Chronic/Restorative**	**2**	**Intolerable Risk**	**HP**	**Health Professional**
Date:	☐ **Palliative**				

Risk Factors	**Comment on strengths, resources available/being used:**	**Level of Risk**		
		CI	**CG**	**HP**
1. PERSONAL FACTORS:				
• AGE: increasing age, particularly > 85 y.o.	In general, risk tends to increase with increasing age and in older women.	N/A	N/A	N/A
• GENDER: female > male		N/A	N/A	N/A
FUNCTIONAL STATUS:				
• Deficits in personal care and I/ADL's.				
• Decreased mobility – include impaired balance, falls				
• Decreased limb function – lower> upper limb function				
• Decreased vision and hearing				
• Decreased communication abilities				
MENTAL STATUS:				
• Memory loss				
• Decreased organizational abilities including initiation				
• Decreased decision-making abilities – includes insight/judgement				
• Depression				
• Anxiety				
• Thought content: paranoia > suspiciousness				
• Altered behaviour-multiple-particularly aggression				
HEALTH STATUS:				
• Self assessment (good to poor) correlates with risk				
• Increased complexity of disease → symptoms, resulting disability				
• Particular diseases – heart disease, stroke, diabetes, cancer, Parkinson's, COPD				
• Frequent emergency visits or within last month				
• Frequent hospitalizations or within last 6 months				
• Frequent visits to GP				
• Poor nutrition				
• Impaired oral/dental health				

Risk Factors	Comment on strengths, resources available/used	Level of Risk		
		Cl	**CG**	**HP**
RISK-TAKING BEHAVIORS:				
• Smoking				
• Substance abuse-alcohol, drugs (street, OTC. Rx)				
• Medication-seeking, non-compliance (also with other treatments)				
• Medical care - no GP; underuse				
• Self Neglect				
• Services-reluctant; refuses				
• Maintaining abusive relationships				
• Lack of contingency plans				
• Driving-appears to be unsafe				
OTHER PERSONAL FACTORS				
2. EXTERNAL FACTORS				
SOCIAL CONDITIONS:				
• Living alone or with elderly spouse				
• Little or no family/friend contact				
• Caregiver burden				
• Family Conflict				
• Neglect/abuse				
• Social isolation				
• Financial difficulties				
• Lack of appropriate surrogate decision-maker				
ENVIRONMENTAL CONDITIONS:				
• Home safety: disrepair, objects-mobility, fire				
• Infestations				
• High crime neighborhood				
• Insecure about housing-eviction, high rent				
• Homelessness				
MEDICATIONS FROM DR.:				
• Number/Type (e.g. polypharmacy, use of benzodiazepines)				
OTHER EXTERNAL RISK FACTORS				

draft 7/20/2011

SUMMARY OF RISK ASSESSMENT

OUTCOME APPRAISAL *(Cl = Client, CG = Caregiver, HCP = Health Care Provider*				
Identification of outcome of risk and related risk factors	Cl	CG	HCP	Response: Current and Proposed

There are 3 levels of risk:
0 = No intervention required
1 = Tolerable Risk, intervention may or may not be required
2 = Intolerable Risk – intervention required.

Draft- 7/20/2011

CARE PLAN

(negotiated with client based on client goals and risk assessment info)

GOALS (priorized; based on client goals and risks)	STRATEGIES		RESPON-SIBILITY	COMMENTS	REVIEW DATE
		NEW			
1.					
2.					
3.					
4.					
5.					
6.					

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Appendix B

VANCOUVER COMMUNITY HEALTH SERVICES/COMMUNITY MENTAL HEALTH SERVICES ETHICAL DECISION-MAKING FRAMEWORK AND PROCESS

Introduction

Ethical decision-making is a central aspect of excellence in health care practice. Ethical support must be accessible to all staff working with clients in the community. The Vancouver Community Health Services (VCHS) Ethics Resource Group supports “ethics in practice” for community clients and has interdisciplinary, inter-program and inter-agency representation. It now reports directly to the VCHA Corporate Ethics Committee (effective April 2003).

Ethical thinking, with time, becomes a "way of thinking" for all professional staff. At certain points, staff may experience moral distress, resulting from a perceived inability to resolve or take part in the resolution of an ethical problem. An ethical decision-making framework is one tool or strategy that can be valuable in our day-to-day professional problem solving. The use of a standardized ethical decision-making framework ensures consistency in our approach to complex decision-making, and protects the rights of the clients, their support systems, and professionals.

The VC group has developed an ethical decision making framework and process to assist community health care professionals in decision-making for complex ethical dilemmas. This framework draws on clinical and ethical expertise from both within and outside VC Health Services, integrates appropriate literature, and incorporates the use of the consultation model for practice consultants in VC Health Services. A moral judgement or decision can be reached with a combination of the ethical decision-making framework and these additional guidelines.

Staff are assisted to utilize this decision-making process in ethical decision-making through education, role modeling, clinical/case conferences and discussion etc. Staff and team knowledge, confidence and expertise in ethical problem solving are developed as practice leaders and educators work with staff. Once teams and staff understand this framework, it is hoped that the process will guide day-to-day decision-making in addition to its role in complex ethical situations.

Guidelines for use of the framework/process

This framework/process is intended to be collaborative involving the client, advocates, family, significant others, health professionals, practice consultants, managers, physicians etc. Ideally, the client or client delegate would direct this process. If the client is not able to direct, a trained advocate could be considered to assist him/her.

The framework/process is set up in phases with reflections or considerations for group members included. The attached guidelines/appendix should be used “hand-in-hand” with the framework

A facilitator for this process should be selected carefully.

VANCOUVER COMMUNITY HEALTH SERVICES/COMMUNITY MENTAL HEALTH SERVICES ETHICAL DECISION MAKING FRAMEWORK APPENDIX AND GUIDELINES [1]

I. INTRODUCTION OF ETHICAL PRINCIPLES (PHASE ONE):

The moral principles of bioethics include:

- Autonomy: Self-determination. Respect people's preferences.
- Non maleficence: Do no harm.
- Beneficence: Do good. Prevent, avoid or remove harm. Also includes concept of proportionality- Balance harms and benefits. Maximize good and minimize harm.
- Justice: Treat like cases alike. Be fair.
- Distributive justice: Fairness (for example, related to resource allocation) based on the equal worth of all.
  Equals should be treated as equals. Equity therefore being fairness according to need.
- Veracity: Tell the truth. Don't withhold information. Informed consent.
- Fidelity: Keep promises.
- Utility and futility of intervention.

II. THE FACT-GATHERING GRID (PHASE TWO):

Facts/ objective data are assembled under the following four topics, preferably in a grid.
Consider use of *risk assessment tool*.

Medical/ health issues: What are the health care needs? What is client's diagnosis/prognosis? What are the risks/benefits of intervention? What are the goals of intervention/option? **Relevant principles:** Non-maleficence, beneficence, veracity	**Client/surrogate preferences:** What does the client want? Is there a legally–appointed surrogate decision-maker? What does the surrogate want? Has the client/surrogate been informed and is consent voluntary? **Relevant principle**: Autonomy, veracity
Quality of life: What kind of life will the client have with or without the intervention/option? Whose definition of quality of life? Has quality of life been considered in a holistic way? What is the harm/benefit/futility/utility ratio? **Relevant principles**: Non-maleficence, beneficence, proportionality, veracity, utility, futility	**Contextual features:** Who else is affected? What other costs are involved? (financial, time and energy). What are the professional practice implications? What does the law/legislation say? What are the societal considerations? **Relevant principles:** Non-maleficence, beneficence, justice, veracity

III. PROPOSING OPTIONS/RESOLUTIONS (PHASE THREE):

Propose creative and flexible interventions or options. Start with options that will be least invasive and most likely to address the issue.

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[1] To maximize usefulness, the ethical decision making framework and these guidelines should be used together.

IV. DECISION-MAKING (PHASE FOUR):

Decisions need to be made. The flow of decision-making would consider:

A. Each of these categories as applicable to the situation

Risk (probability x harm)	Competent/ Capable[2]	Mental Illness	Emotional state	Undue Influence	A. Information	HOW MUCH WE INTERFERE
Not permanent or serious or probable. (Tolerable)	Client can understand & appreciate risks/ outcomes/ consequences	None. ↓	Absent ↓	Absent. ↓	Client has full info ↓	Explain. ↓ Argue.
↓ Permanent, & serious & probable (Intolerable)	Understands. ↓ Does not understand.	Mild. ↓ Significant	Seriously impairing.	Seriously impairing.	Client has little or no info .	Pressure. ↓ Physically coerce.

<u>Is the client “encumbered”?</u>

When a person is subject to some “distorting condition” that may affect their decision-making: capability/competency (cognitive factors), mental illness, emotional states, influence, information (lack).

<u>Interference and paternalism</u>

- How strongly an option is presented when a client does not fully support the option.
- Weak: Interfere only if encumbered
- Strong: Interfere with encumbered or interfere in unencumbered if :
  - subsequent gratitude (or)
  - “better off”

The “weak paternalism” view is the desired approach in health care.

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[2] Note that definitions for “capability” or “competency” are often somewhat different according to the source or applicable legislation (eg. Mental Health Act, Adult Guardianship Act, Health Care Consent etc.)

Relating risk to being encumbered to interference, in general

- If risk is present, and capability/competency, mental illness, emotional state, undue influence, and information are at upper end of scales, the interference should be: explain and argue.
- If risk is present, and capability/competency, mental illness, emotional state, undue influence, and information are at lower end of any scale, the interference should be: pressure and coerce.
- Interfere only if the interference is: effective, benefits will be greater than evils, the mildest possible, and not discriminatory.

B. DETERMINE DECISION-MAKING BY/WITH /FOR THE CLIENT:

- Is the client encumbered?
- If not encumbered, client decides for self (or within their "network of support")
- If possibly encumbered, needs further assessment of factors related to this.
- If capability/competency is in question, determine whether the "triggers" for a capability/competency assessment are satisfied:
    - Exhibits behaviour which places person or others at risk
    - Known or suspected impaired decision-making
    - Choices not consistent with prior values
    - Previous attempted solutions failed and capability/competency assessment is last resort
    - Capability/competency assessment and appointment of substitutes will solve the problem

C. Review each ethical principle relative to each issue/option and decide which **principle(s) directs the decision-making for each option :**

Health issues: If intervention/option is harmful to client, withhold. If intervention/option is beneficial to client, deliver. **Principles:** Non-maleficence, beneficence, veracity	**Client/surrogate preferences:** If client/family/surrogate want intervention/option, then deliver. If client/family/surrogate do not want intervention/option, then withhold. **Principles:** Autonomy, veracity
Quality of life: Same as health issues. **Principles:** Non-maleficence, beneficence, proportionality, veracity, utility, futility	**Contextual issues:** If intervention/option is harmful to society, withhold. If intervention/option is beneficial to society, deliver. If intervention/option shows partiality, withhold. **Principles:** Non-maleficence, beneficence, justice, veracity

D. In situation where principles are in conflict, apply the following way of prioritizing principles

Dealing with principles in conflict:

- If the facts are clear and the principles all point to the same course of action, there is no moral problem. If the facts are unclear or principles conflict, there is a moral problem.
- For example, if what the client wants may be harmful to society-to start a fire in his seniors' apartment- then there is no moral problem.
- If the client wants to be allowed to live at risk, there may be a moral problem.

In case of conflict, the standard way of prioritizing principles with decisions is:

Intervention/choice/option

INTERVENTION/CHOICE/OPTION may not be offered if futile, costly, harmful to client or others, or compromises professional integrity.

INTERVENTION/CHOICE/OPTION may be offered, if not excluded (in left section). Decisions will be made by dividing into following areas.

<u>Capable/Competent</u>

Capable/ competent clients are decision-makers.

<u>Incapable/Incompetent</u>

If client is incapable/ incompetent, health care professionals, family, or surrogate/ advocate are involved in decision-making.

Decisions may be made based on either of the following kinds of judgement:

Substituted judgement (what the client would choose if competent- *the preferred choice).*

OR

Best interest judgement (what the reasonable person in that situation would choose).

E. Choose the intervention/option(s):

- There will be option(s) that become predominant relative to each issue after the principles are applied as indicated above.
- It will still be necessary to examine the option(s) in more detail within the decision-making group for:
  - The components of the option(s)
  - How the option(s) will actually solve the issue(s) or what may be the "critical success factors"
  - Feasibility of resources, availability etc.
  - Other criteria that are appropriate to the situation
- Have a back-up plan, if necessary.
- Have a longer range plan, if necessary.

V. IMPLEMENTATION/ACTION/EVALUATION PHASE (PHASE FIVE)

- Review the principles that have been applied.
- Document the process carefully and plan for follow-up.
- Communicate with all team members. Support each other. Arrange formal debriefing as required.
- Evaluate outcomes and change plan as necessary. Interventions may need to change as available information is updated.

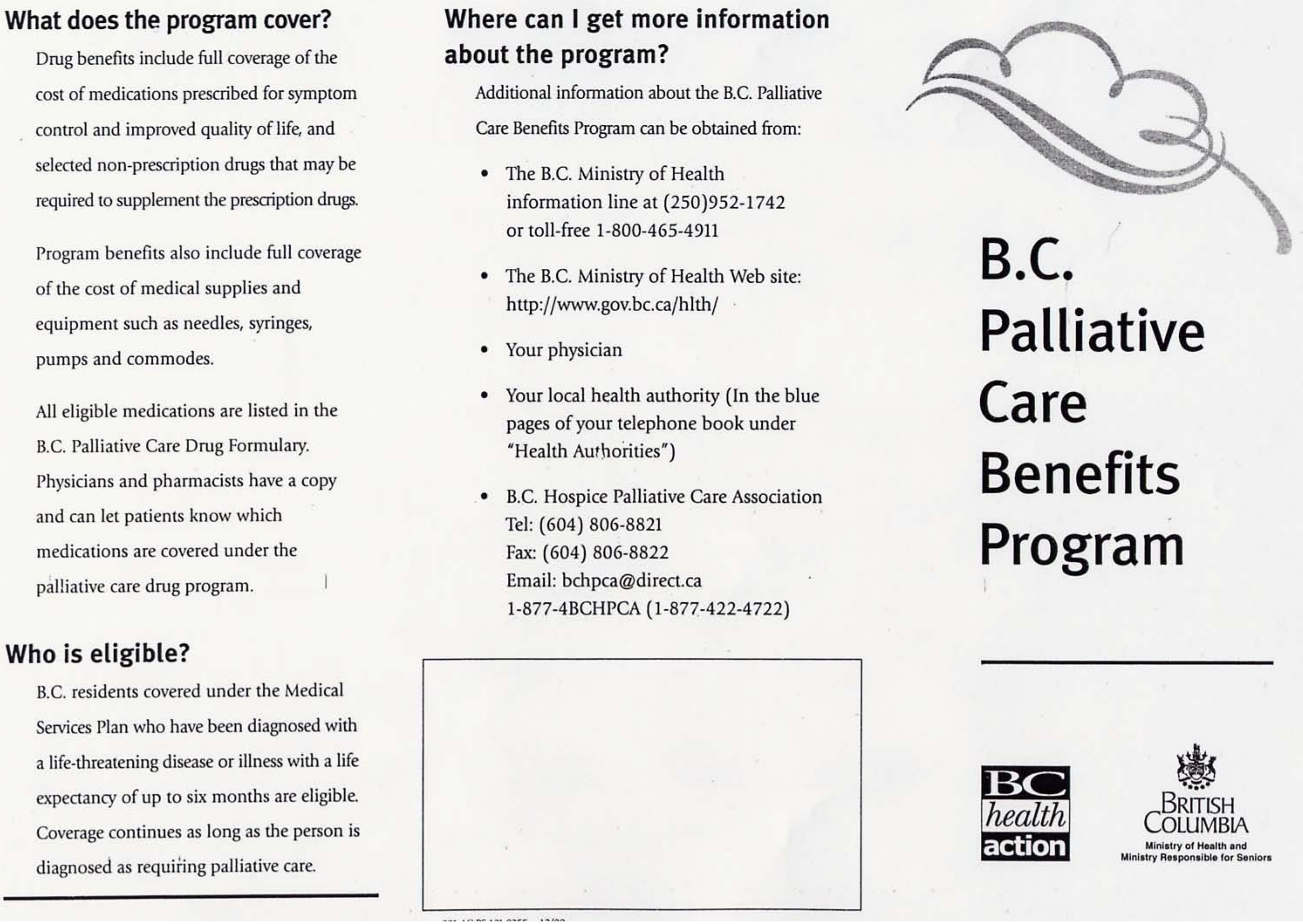
Ethical Decision Making Framework

Vancouver Community Health Services/Community Mental Health Services/ Ethics Resource Group

(Adapted from original work of: Dr. A. Browne, 1997; Jonsen, Winslade, & Siegler, 1989; Dr. Michael McDonald, 1998)

Planning/Phase 1 **Introduction of process/ "framing the issue(s)"**	**Phase 2** **Fact-gathering/ application**	**Phase 3** **Propose options**	**Phase 4** **Decision-making**	**Phase 5** **Implementation/ Action/evaluation plan**
The process				
Prephase-Planning for meeting: 1. Select an experienced facilitator. 2. Invitations to the meeting should be inclusive of all those involved. 3. Consider if the client will be present or how he/she will be represented. 4. Do staff need to meet separately first to prepare? 5. Plan for emotional upset/conflict. 6. Set ground rules for discussion. **Phase one:** 1. Introductions of all present. 2. Introduction of the decision-making process that will be used. 3. Clarification of personal, professional, cultural and organizational values/biases and assumptions. 4. "Why are we here today?" - What appear to be the main concerns? Round- table discussion.	1. Confirm the main issues. 2. Using the guidelines/appendix to assist, in grid format, gather data according to health needs/care indications, contextual issues, client preferences, and quality of life categories. 3. Utilize *risk assessment tool* as necessary. 4. Identify appropriate ethical principles in each area of grid.	1. Propose possible options. 2. Tailor the options to the client's particular circumstances. 3. Consider any new information that has come up that may change the way options may be considered.	1. Establish criteria for evaluating options/choices, using the appendix/guidelines to assist. 2. Apply and priorize ethical principles to each area of grid, according to guidelines/appendix. 3. Using the criteria and guidelines/appendix, decide on the best choice with the information available. 4. If necessary, establish a back-up plan, in case the chosen option fails.	1. Decide who will be responsible for what. 2. Plan for implementation and evaluation of your decision(s). 3. Establish plan for possible current and future debriefing for those involved. 4. Articulate how the choice will evolve over time and when it should be re-evaluated. 5. Document process clearly.
Considerations and reflections for group members				
1. How might my values, assumptions and biases impact on this process? Can I set them aside? 2. Be alert and sensitive. Don't jump to conclusions and clarify assumptions. 3. How is trust built within the group, based on respect and an egalitarian approach where all opinions are valued?	1. Do I see anybody being taken advantage of? 2. Am I harming anybody or treating him or her paternalistically? Am I behaving in a caring manner? 3. Can I talk to someone else that I trust or get moral insight from someone that I consider of great moral integrity? 4. Avoid assumptions and discussions re: client's capability/competency until Phase 4.	1. Will the options that are proposed help resolve the issue in the least invasive way? 2. Try to be creative and flexible when proposing options. 3. Remain non-judgmental about options. 4. Realize that some situations can not be totally solved. Do options reflect organization's policies and procedures?	1. Perform a sensitivity analysis, including: Would a good person do this? What if everyone did this? Does this seem right? Am I uncomfortable with the choice? What is making me uncomfortable? Has client preference been given appropriate weight? 2. How does the decision reflect the "ethical conscience" of the organization?	1. Have I informed everyone who should be informed? 2. Live with the decision. Accept shared responsibility for the decision. 3. How can the client and those involved in assisting the client be supported though the implementation of the chosen option? 4. Does anyone need "debriefing"? 5. Learn from failures as well as successes.

APPENDIX C



What does the program cover?

Drug benefits include full coverage of the cost of medications prescribed for symptom control and improved quality of life, and selected non-prescription drugs that may be required to supplement the prescription drugs.

Program benefits also include full coverage of the cost of medical supplies and equipment such as needles, syringes, pumps and commodes.

All eligible medications are listed in the B.C. Palliative Care Drug Formulary. Physicians and pharmacists have a copy and can let patients know which medications are covered under the palliative care drug program.

Who is eligible?

B.C. residents covered under the Medical Services Plan who have been diagnosed with a life-threatening disease or illness with a life expectancy of up to six months are eligible. Coverage continues as long as the person is diagnosed as requiring palliative care.

Where can I get more information about the program?

Additional information about the B.C. Palliative Care Benefits Program can be obtained from:

- The B.C. Ministry of Health information line at (250)952-1742 or toll-free 1-800-465-4911
- The B.C. Ministry of Health Web site: http://www.gov.bc.ca/hlth/
- Your physician
- Your local health authority (In the blue pages of your telephone book under "Health Authorities")
- B.C. Hospice Palliative Care Association
  Tel: (604) 806-8821
  Fax: (604) 806-8822
  Email: bchpca@direct.ca
  1-877-4BCHPCA (1-877-422-4722)

B.C. Palliative Care Benefits Program

BC health action

BRITISH COLUMBIA
Ministry of Health and
Ministry Responsible for Seniors

What is the B.C. Palliative Care Benefits Program?

In December 2000, the provincial government announced the introduction of the B.C. Palliative Care Benefits Program, effective Feb 1, 2001. The program supports and enables individuals in the end-stage of a life-threatening illness or disease to remain at home by covering the cost of medication, medical supplies and equipment – all at no charge.

Previously, dying at home surrounded by family and friends was often not an option because of the cost of prescription drugs, over-the-counter drugs and medical supplies. These are supplied at no cost to patients in hospitals and care facilities, but not to patients at home.

How does someone apply?

The patient's physician must certify they meet the criteria for coverage under this program. For drug benefits, the physician submits an application form directly to Pharmacare on behalf of the patient. The physician also sends a copy of the application form to the local health authority. This application is the referral for coverage of medical supplies and equipment benefits.

How are prescription and non-prescription drugs received?

Once the application form is processed and entered on PharmaNet, a family member or the patient can have the prescription filled at no additional cost.*A prescription from the patient's physician is also needed for eligible medical supplies and over-the-counter drugs.

*(Some community pharmacies may charge dispensing fees and drug costs that exceed amounts covered by the program. You may wish to discuss these with the pharmacy before filling the prescription).

Where does someone obtain medical supplies and equipment under the program?

Once the health authority receives the application from the patient's physician, a home care nurse or a nurse from the palliative care program will contact them. Arrangements will be made for a home visit to determine which medical supplies and equipment are needed.

What is *not* covered by the program?

The B.C. Palliative Care Drug Program does not cover:

- Drug products not listed in the B.C. Palliative Care Drug Formulary
- Medications for palliative patients receiving care in an acute hospital or continuing care residential facility (the hospital or care facility covers these costs).

BRITISH COLUMBIA **Ministry of Health Services**

Mailing Address:
BC Palliative Care Program
P.O. Box 9655, Station Prov. Govt.
Victoria, BC, V8W 9P2

BC PALLIATIVE CARE DRUG PROGRAM APPLICATION

SEE REVERSE SIDE FOR INFORMATION REGARDING THE BC PALLIATIVE CARE DRUG PROGRAM

Before completing this application, please read the information on the reverse side. All sections must be completed. The application will be returned to the physician if information is omitted.

To ensure this application reaches us as quickly as possible, please **fax to: (250) 952-2861**

Alternatively, you can send by mail to the above address.

This facsimile is Doctor-Patient privileged and contains confidential information intended only for the recipient. Any other distribution, copying or disclosure is strictly prohibited. If you have received this fax in error, please destroy it and notify the physician.

APPLICANT'S PERSONAL INFORMATION (please print)

LAST NAME	FIRST NAME	MIDDLE NAME
PERSONAL HEALTH NUMBER (PHN)	DATE OF BIRTH YYYY MM DD	GENDER ☐ MALE ☐ FEMALE
MAILING ADDRESS		
CITY	PROVINCE	POSTAL CODE
I understand the benefits I am eligible for under this program. APPLICANT'S SIGNATURE	TELEPHONE NUMBER AREA CODE	DATE YYYY MM DD

If the patient did not complete this section, Legal Representative complete the following information:

LAST NAME (PLEASE PRINT)	FIRST NAME	MIDDLE NAME	TELEPHONE NUMBER

CERTIFICATION BY PHYSICIAN - to be completed by physician

PRIMARY DIAGNOSIS	OTHER DIAGNOSIS

I hereby request coverage under the BC Palliative Care Drug Program for the above identified patient and certify that this patient meets the criteria for coverage under the BC Palliative Care Drug Program as outlined on the reverse side of this form.

REFERRED TO LOCAL HOME CARE? ☐ YES ☐ NO	SIGNATURE OF PHYSICIAN	
NAME & MAILING ADDRESS	APPLICATION DATE YYYY MM DD	PRESCRIBER'S TELEPHONE # AREA CODE
	PRESCRIBER'S COLLEGE ID #	PRESCRIBER'S FAX # AREA CODE

Personal information on this form is collected for the operations of the BC Palliative Benefits Program, Ministry of Health and Ministry Responsible for Seniors. The personal information will be used to enroll the applicant as a beneficiary of and to initiate coverage under the Program. Personal information will be released to Pharmacare and Continuing Care for the provision of drug benefits and, where necessary, to the local Continuing Care office for the determination of medical supply and equipment needs. If you have any questions about the collection of personal information on this form, contact the BC Palliative Care Benefits Program, 1515 Blanshard St., Victoria, B.C. V8W 3C8. Phone: 250-952-1742 or 1-800-465-4911.

This information will be used and disclosed in accordance with the *Freedom of Information and Protection of Privacy Act.*

Before completing this application form, please read the following information

1. **What does the BC Palliative Care Drug Program cover?**
   The BC Palliative Care Drug Program provides coverage for prescribed medications that support symptom control and quality of life and selected non-prescription medications required along with those prescribed medications.

2. **Who is eligible for the BC Palliative Care Drug Program?**
   Persons eligible for this program are BC residents who:
   - Are enrolled in MSP
   - Are living at home
   - Have been diagnosed at the terminal stage of a disease or illness
   - Have a life expectancy of up to six months, and
   - Consent to the focus of care as palliative and not treatment aimed at cure.

   Your physician must certify that you meet the criteria for coverage under this program

3. **What will this coverage cost?**
   The BC Palliative Care Drug Program provides coverage for eligible medications at no charge to you.

4. **When does coverage for my drug benefits start?**
   Coverage for benefits begins as soon as the application form is processed by the Ministry of Health.

   Coverage of benefits will continue as long as you are diagnosed as requiring palliative care.

5. **How do I receive coverage for medical supplies and equipment?**
   Your physician must make a referral directly to the local health authority for coverage of medical supplies and equipment. You will be assessed by a home care nurse or nurse from the palliative care program who will determine what medical supplies and equipment are required.

6. **For enquires and confirmation of enrollment, please phone:**
   Vancouver/Lower Mainland (604)682-6849
   Victoria (250) 952-2866
   Rest of BC 1-800-554-0250

Appendix D

Employment Insurance

The Employment Insurance Compassionate Care Benefit

What is the Compassionate Care Benefit?

One of the most difficult times anyone can face is when a loved one is dying or at risk of death. The demands of caring for a gravely ill or dying family member can jeopardize the employment of Canadians and the economic security of their families. The medical and palliative care community is only too aware of the stress that family members feel resulting from conflicting family and work responsibilities. The Government of Canada believes that, during such times, Canadians should not have to choose between keeping their jobs and caring for their families.

The Employment Insurance (EI) Compassionate Care benefit will be available to EI-eligible workers who must be absent from work to provide care or support to a child, parent, spouse or common-law partner who has a serious medical condition with a significant risk of death.

When will the benefit start and how long will it last?

Beginning January 4, 2004, up to six weeks of the Compassionate Care benefit will be made available for EI-eligible workers in a given family to share when a parent, spouse, child or common-law partner falls gravely ill.

Why six weeks?

Several factors were considered in determining the appropriate benefit period, including medical evidence, best practices in the public and private sectors, and that the majority of Canadians who take time off work to care for a gravely ill family member take six weeks or less.

Who will be able to get the new benefit

To be eligible for the new benefit, workers must have paid EI premiums and have worked 600 hours. Self-employed fishers will also be eligible for the new benefit.

The new benefit could be paid in relation to caring for one of the following gravely ill family members:

- a spouse or common-law partner;
- a parent;
- the spouse or common-law partner of a parent;
- a child; or
- a child of the spouse or common-law partner.

Will a medical certificate be needed?

A *Medical Certificate for Employment Insurance Compassionate Care Benefits* from n attending doctor or, where applicable, medical practitioner will be required. The certificate must indicate that the ill family member has a serious medical condition with a significant risk of death within 26 weeks (six months) and that the ill family member requires the care or support of one or more family members.

Human Resources Development Canada
Développement des ressources humaines Canada

Canada
IN-062-12-03

For Employment Insurance benefit purposes, care or support is defined as:

- providing or participating in the care of the patient, or
- arranging for the care of the patient by a third-party care provider, or
- providing psychological or emotional support to the patient.

Can only one person per family claim the benefit?

No. The new benefit will provide families with greater choices and flexibility during one of the most difficult times Canadians can face.

The six weeks of the Compassionate Care benefit can be made available when a family member falls gravely ill. The benefit can be taken by one individual or shared with other EI-eligible family members if they fit the relationship described above. For example, the six weeks can be shared between a brother and sister to care for a parent or the six weeks can be taken by one or the other – it's up to the family members to decide. Also, the benefit can be taken at the same time or in different weeks.

Why is the benefit restricted to those caring for a parent, child or spouse?

The majority of Canadians facing this type of a crisis are caring for a child, parent or spouse.

Will there be a limit as to when the six weeks can be taken?

Again, flexibility has been built into the Compassionate Care benefit.

A 26-week (six months) "window" in which the benefit's six weeks can be taken will be applicable. The window will cover the 26-week period identified by the doctor during which there is a need for one or more family members to provide care or support to the gravely ill family member. Within those 26 weeks, the family members can decide on how, when and by whom the 6 weeks should be taken.

Will there be a waiting period before the benefit is paid?

As with other EI benefits, there will be a waiting period of two weeks (over and above the benefit's proposed six weeks). When the benefit is shared, the first family member who applies will have to serve the waiting period. If two or more family members apply at the same time, they must decide who will serve the waiting period.

If family member(s) who are sharing the benefit **did not** serve the waiting period, then a waiting period may apply if they request another type of benefit (i.e., regular benefits).

Will jobs be protected?

Part III of the *Canada Labour Code*, which applies to employers and employees in workplaces under **federal jurisdiction**, has been amended so that employees will be entitled to up to eight weeks of compassionate care leave and job protection beginning January 4, 2004.

Federal employers may not dismiss, suspend, lay off, demote or otherwise discipline an employee for taking compassionate care leave or take this into account in any decision to promote or train the employee.

An employee who takes a period of compassionate care leave must be reinstated in his or her former position, or be given a comparable position in the same location and with the same wages and benefits.

Some provincial/territorial labour codes currently provide some job protection for workers for this type of family situation.

How will employers be affected?

The absence of adequate supports for work-family balance is costly to business and results in greater absences, reduced productivity and, in some cases, the loss of valuable employees. Business often bears some of the cost of employees who are trying to balance workplace/family responsibilities when caring for a gravely ill family member. The flexibility for claimants that has been incorporated in the new benefit (i.e., sharing the benefit and working while on claim) is responsive to business and accommodates its ability to retain a skilled work force.

Will the new benefit be available if the gravely ill family member lives outside Canada?

It is recognized that as a culturally diverse nation, some Canadians have close family members who live outside Canada. The new benefit will also be available to EI-eligible workers if the gravely ill family member (as described above) does not live in Canada. The same eligibility rules will, of course, apply.

Will the new benefit be evaluated?

Human Resources Development Canada (HRDC) will evaluate the new Compassionate Care benefit. It is important to note that the new benefit is effective January 2004 and, as such, HRDC will not have a complete fiscal year of data to examine until after 2004-2005.

In addition, the Canada Employment Insurance Commission produces an annual Monitoring and Assessment Report to assess how the EI program is functioning. The report will include ongoing analysis of the new Compassionate Care benefit.

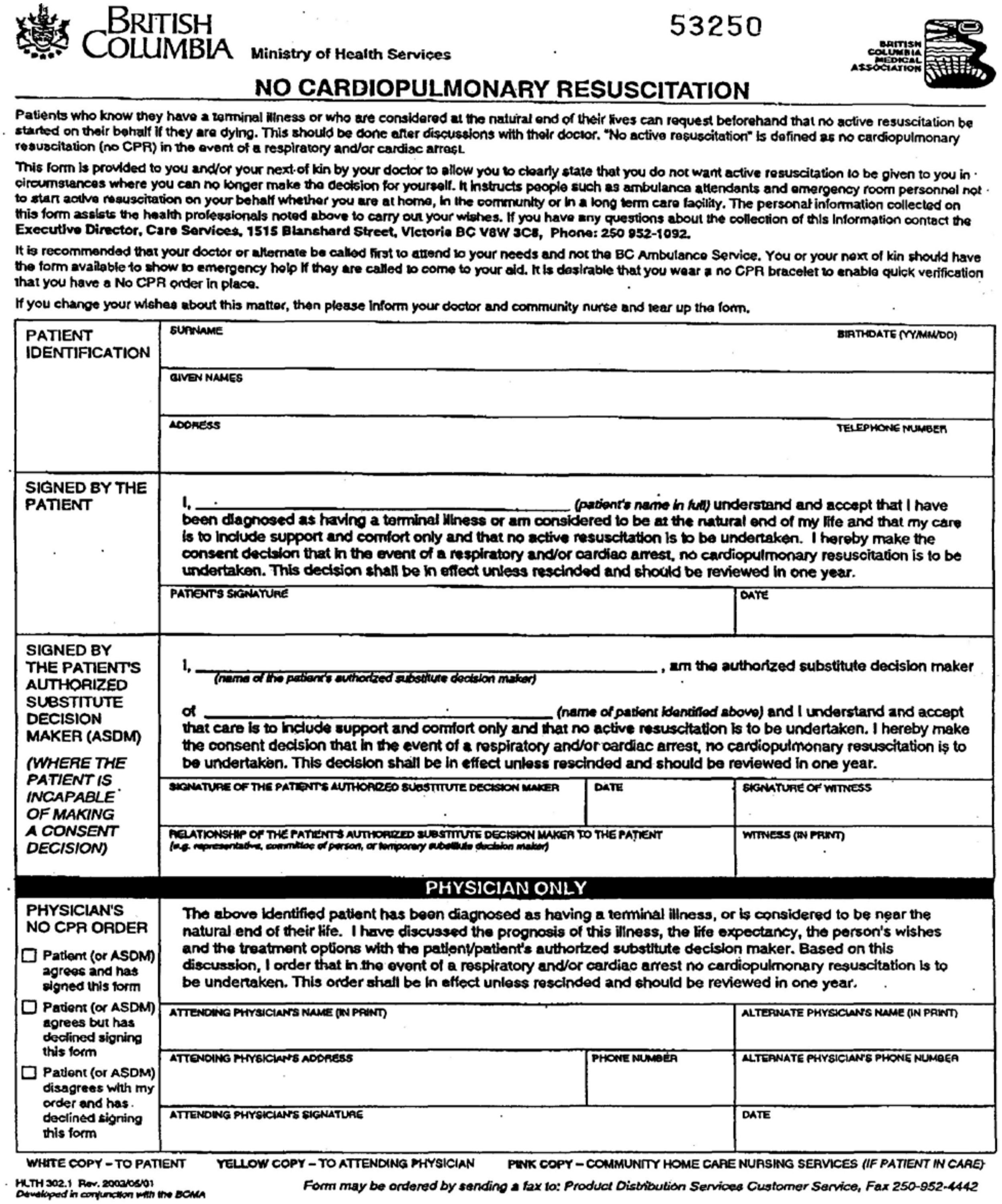
What is the application process?

When the new benefit becomes available (January 4, 2004), claimants will apply for it as they do for other EI benefits (i.e., through the Internet www.hrdc.gc.ca or through their local HRDC).

For more information

Please check the HRDC Web site at www.hrdc.gc.ca , or call 1 800 206-7218, or visit your local HRDC.

APPENDIX E



BRITISH COLUMBIA Ministry of Health Services

53250

BRITISH COLUMBIA MEDICAL ASSOCIATION

NO CARDIOPULMONARY RESUSCITATION

Patients who know they have a terminal illness or who are considered at the natural end of their lives can request beforehand that no active resuscitation be started on their behalf if they are dying. This should be done after discussions with their doctor. "No active resuscitation" is defined as no cardiopulmonary resuscitation (no CPR) in the event of a respiratory and/or cardiac arrest.

This form is provided to you and/or your next-of kin by your doctor to allow you to clearly state that you do not want active resuscitation to be given to you in circumstances where you can no longer make the decision for yourself. It instructs people such as ambulance attendants and emergency room personnel not to start active resuscitation on your behalf whether you are at home, in the community or in a long term care facility. The personal information collected on this form assists the health professionals noted above to carry out your wishes. If you have any questions about the collection of this information contact the **Executive Director, Care Services, 1515 Blanshard Street, Victoria BC V8W 3C8, Phone: 250 952-1092.**

It is recommended that your doctor or alternate be called first to attend to your needs and not the BC Ambulance Service. You or your next of kin should have the form available to show to emergency help if they are called to come to your aid. It is desirable that you wear a no CPR bracelet to enable quick verification that you have a No CPR order in place.

If you change your wishes about this matter, then please inform your doctor and community nurse and tear up the form.

PATIENT IDENTIFICATION

SURNAME | BIRTHDATE (YY/MM/DD)

GIVEN NAMES

ADDRESS | TELEPHONE NUMBER

SIGNED BY THE PATIENT

I, __________________________________ *(patient's name in full)* understand and accept that I have been diagnosed as having a terminal illness or am considered to be at the natural end of my life and that my care is to include support and comfort only and that no active resuscitation is to be undertaken. I hereby make the consent decision that in the event of a respiratory and/or cardiac arrest, no cardiopulmonary resuscitation is to be undertaken. This decision shall be in effect unless rescinded and should be reviewed in one year.

PATIENT'S SIGNATURE | DATE

SIGNED BY THE PATIENT'S AUTHORIZED SUBSTITUTE DECISION MAKER (ASDM)

(WHERE THE PATIENT IS INCAPABLE OF MAKING A CONSENT DECISION)

I, ____, am the authorized substitute decision maker
(name of the patient's authorized substitute decision maker)

of __________________________________ *(name of patient identified above)* and I understand and accept that care is to include support and comfort only and that no active resuscitation is to be undertaken. I hereby make the consent decision that in the event of a respiratory and/or cardiac arrest, no cardiopulmonary resuscitation is to be undertaken. This decision shall be in effect unless rescinded and should be reviewed in one year.

SIGNATURE OF THE PATIENT'S AUTHORIZED SUBSTITUTE DECISION MAKER | DATE | SIGNATURE OF WITNESS

RELATIONSHIP OF THE PATIENT'S AUTHORIZED SUBSTITUTE DECISION MAKER TO THE PATIENT
(e.g. representative, committee of person, or temporary substitute decision maker) | WITNESS (IN PRINT)

PHYSICIAN ONLY

PHYSICIAN'S NO CPR ORDER

- ☐ Patient (or ASDM) agrees and has signed this form
- ☐ Patient (or ASDM) agrees but has declined signing this form
- ☐ Patient (or ASDM) disagrees with my order and has declined signing this form

The above identified patient has been diagnosed as having a terminal illness, or is considered to be near the natural end of their life. I have discussed the prognosis of this illness, the life expectancy, the person's wishes and the treatment options with the patient/patient's authorized substitute decision maker. Based on this discussion, I order that in the event of a respiratory and/or cardiac arrest no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect unless rescinded and should be reviewed in one year.

ATTENDING PHYSICIAN'S NAME (IN PRINT) | ALTERNATE PHYSICIAN'S NAME (IN PRINT)

ATTENDING PHYSICIAN'S ADDRESS | PHONE NUMBER | ALTERNATE PHYSICIAN'S PHONE NUMBER

ATTENDING PHYSICIAN'S SIGNATURE | DATE

WHITE COPY – TO PATIENT YELLOW COPY – TO ATTENDING PHYSICIAN PINK COPY – COMMUNITY HOME CARE NURSING SERVICES *(IF PATIENT IN CARE)*

HLTH 302.1 Rev. 2003/06/01
Developed in conjunction with the BCMA

Form may be ordered by sending a fax to: Product Distribution Services Customer Service, Fax 250-952-4442

STAN AND BETTY : TWO LIVES

Introduction

Mr. Stan Johnson is a 73 year old Caucasian retired millwright. He worked in the lumber industry and has a grade 8 education. He chain smokes 3-4 packs/day. His first wife died of breast cancer 15 years ago. Mrs. Betty Wilson, 65, lives common-law with Stan. She is First Nations, and has a Grade 10 education. She married young and raised 6 children in her remote Northern village. She is an excellent cook, which she enjoys greatly and also makes jewellery. She has type 2 diabetes mellitus and congestive heart failure and is mildly overweight. She has shortness of breath with exertion. Her first husband was alcoholic and died of liver cirrhosis 12 years ago. After her husband died, she became friendly with Stan and moved in with him 10 years ago before moving o the small rural town in which they now reside. He drives, she does not.

Previously, Stan did most of the grocery shopping and housework because of her difficulty with ambulation and bending over. Betty does the cooking. Her children and siblings still live in their remote village. Stan has a daughter Laura, 44, who lives in town. He has one son who lives in a large city 800km away, and who has had little contact with his father. Laura has two teenaged children. Laura is very devoted to Stan but has had some issues with his relationship with Betty, although she admits “Betty has been good for him”.

Stan is a member of the Legion and goes in every week for a beer, and plays darts. Betty has few other contacts in town, has missed her family but was willing to move with Stan so that he could be closer to Laura. Betty’s father was a spiritual leader within his Nation. She is converted to Anglicanism and attends church regularly.

Care for Elders Module Evaluation

Module Title: **Date:** **Location:**

Please rate the following statements (✓):	***Strongly Disagree***	***Somewhat disagree***	***Neutral***	***Somewhat Agree***	***Strongly Agree***	***N/A***
1. The organization, room, and timing of the session was adequate						
2. The pre-reading package covered information that was new to me						
3. The pre-reading package was well organized and easy to read						
4. Today's session DID improve my knowledge of interdisciplinary roles, responsibilities and team dynamics						
5. The facilitator was effective in keeping discussion moving forward						
6. The facilitator provided new, critical information as needed						
7. The case complexity or difficulty was appropriate for my level						
8. The discussion in my group was helpful for my learning						

1. Please name **two** changes in your own practice that you will implement as a result of what you learned today.

   1. ______________________________

   2. ______________________________

2. Please name **two** ways in which this session could be improved.

   1. ______________________________

   2. ______________________________

Please return evaluation forms to: Division of Community Geriatrics, Department of Family Practice, UBC
c/o GPOT-CP5D, 855 West 12th Ave., Vancouver, B.C. V5Z 1M9