Palliative Journey Resource Guide

A list of palliative support resources for individuals nearing the end of life and their families and caregivers.

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“End of Life Care does not begin with Palliative Care, it begins with Community”  
*Jules Verne*
End of life information and resources for individuals, families and caregivers.

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What is Palliative Care?
Palliative care is aimed at relieving suffering and improving the quality of life for persons who are living with, or dying from, advanced illness or are bereaved. (Canadian Hospice Palliative Care Association).

Palliative care is the special care of a person whose disease cannot be cured. Palliative care provides comfort and support to the person and family. Palliative care does not hasten nor delay death. The goals of palliative care are to: ease pain and other symptoms (such as depression, upset stomach, shortness of breath, etc.), to help the person to have a clear mind and to support the person, family and friends.

“You matter because you are. You matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die”

_Dame Cicely Saunders_

_Founder of the Modern Hospice Movement_
Purpose of this Guide

One of the most important things that can help people and their families and caregivers near the end of life is timely information and education about the journey.

This resource guide is a list of on-line resources that is meant to assist individuals, family members and caregivers to navigate the vast amount of palliative care and end of life information and services available within British Columbia. (Note that the content in this guide is not considered an exhaustive list).

This document has purposefully been divided into a number of major sections that follow the different stages that a person with advancing illness, who is approaching the end of their life, will likely experience.

The sections include:

- Describing the Palliative Journey:
  - Cancer
  - Non-cancer
- The Importance of Seeking Support
- Tough Decisions: Allow a Natural Death
- Planned and Expected Deaths: Options and Choices to Consider
- Navigating the System: Care Services at the End of Life
- Caregiving and Supports
- What to Expect in the Final Days and Hours
- After Death: Grief and Bereavement Supports

This resource is meant to be used electronically in order to be able to access the links to the various documents, videos and websites. If you do not own a personal computer, you may still be able to access one at your local public library or ask a family member to assist you.
Describing the Palliative Journey

The palliative journey can be variable in nature and length of time. For some people, the journey begins with an unexpected diagnosis of cancer for which there is no cure. Others may have lived for years with cancer or other chronic diseases that slowly deteriorate the heart, lungs, kidney or brain, and as the disease progresses, independent daily living becomes more difficult. Each journey is unique to the individual.

The Cancer Palliative Journey
The palliative journey for people living with advancing cancer begins when they are told by their doctor that active treatment to achieve a cure is no longer possible. This is the time to revisit goals of care.

Conversations shift and may include re-looking at advanced care plans, talking about the preferences and choices for what is most important to the person, how they wish to live out their remaining time, what arrangements need to be made and where they wish to die.

This is a time when the person, their family and health care professionals will talk openly about the plan to manage pain and other symptoms and identify which treatment and medication options may continue but with the focus now being on comfort rather than the purposes of cure.

As the person and family adjust to the news, they will start to plan for an expected death in the coming weeks and months. Paying attention to the emotional and spiritual needs during this transition in care is extremely important. This Resource Guide contains many strategies and supports to help people with advancing cancer and their family during this challenging time.

The Non-Cancer Palliative Journey
The number of adults living with advancing chronic illness, such as heart, lung and kidney disease or dementia is increasing as they survive into old age. As individuals continue to age, there is a greater risk for known illnesses such as congestive heart failure or chronic obstructive lung disease to worsen, and for others to develop for example, Alzheimer’s disease and other related dementias.

The last year of life for these individuals is often marked by a progressive slow decline with frequent medical appointments, visits to the Emergency Department and/or admissions to hospital. Their condition may suddenly worsen, and then stabilize and recover, but often the person’s condition does not return back to where they were before these repeated health crises. End of life planning is an important part of good care for these individuals and their families, and this Resource Guide provides tips and information in coping with this unpredictable and fragile journey.
The Importance of Seeking Support

People living with advancing illness, family members and caregivers all require some support. The palliative journey is frequently an uneasy and emotional one for all involved. Knowing what lies ahead, understanding what symptoms can be expected and need to be addressed, and how the disease may progress is important to manage daily care needs and achieve best quality of life for both the individual and the family and caregivers.

Addressing Symptoms and Health Concerns
Whether it is sorting out a variety of new symptoms and concerns, or addressing a longer standing health condition, talking with a health care professional that can assess and make recommendations is essential. The Canadian Virtual Hospice site provides information on a number of symptoms and health areas.

Symptoms and Health Concerns

Attending Emotional Health Issues
The Canadian Virtual Hospice site also hosts a broad range of topics that support emotional health, including grief, guilt, anger, forgiveness, hope, denial and anxiety, as well as many others.

Emotional Well-Being

Living with Limited Time

The BC Cancer Agency (BCAA) Counselling staff have created a library of relaxation CDs and patient handouts on topics such as anxiety, coping with anger, deep breathing exercises and muscle relaxation, tips to manage stress and strategies to sleep.

BCAA Patient handouts to cope with treatment and beyond

Relaxation CDs

Considering Spiritual Health Issues
A life-threatening illness can raise questions of meaning and purpose in fresh and urgent ways and cause spiritual distress. Even when one holds no particular religious beliefs, there may be a need to deal with issues of a spiritual nature, such as identity, suffering and hope. What makes these issues spiritual is that they raise questions about the meaning of life – life in general and the person’s life in particular.

Spiritual Health Resources
Tough Decisions: Allow a Natural Death

As health deteriorates, making a decision to express one’s wishes to loved ones and to health professionals about what type of care is desired will be one of the most difficult things a person has to do. Most of us dislike thinking about our own death. Many thoughts and emotions may surface, yet it is a fact of life that one day we will all die.

Considering Hospice Palliative Care

Advanced Care Planning – My Voice Planning Guide

Advance care planning is making a plan for future health care while one is still able to make health care decisions for him or herself. It can be hard to think and talk about the end of one’s life but it’s best to do these things before a crisis occurs. Talk with loved ones and health professionals about the kinds of care that is or is not preferred, including conversations to continue or to abandon life-support measures. Don’t assume that family and health professionals know what is wanted.

My Voice Planning Guide – Expressing my wishes for future health care treatment

Medical Order Scope of Treatment (MOST)

MOST is a physician order that tells health care providers what treatment is to be provided. It is intended to be completed for persons who are seriously ill, or have health concerns or circumstances that are important to communicate to their health care team. To better prepare for future treatment options, talk with the doctor and health care team to better understand current health condition, possible treatments, best options for comfort care, and ensure they are aware of personal preferences for future care and treatment. A copy of the MOST will also be provided to the individual or family member by the doctor and can be kept in the home in or by the side of the fridge, which is the most common spot for visiting health professionals to look for it. Information about MOST

Making Decisions about Receiving Cardiopulmonary Resuscitation (CPR) and Life Support

Talk to your doctor or health care team about advancing illness, specific treatment options, and chances for recovery. A key part of this process is including family in these conversations to discuss options together and clearly state end of life wishes and preferences. Some people who are facing death have strong and definite feelings about CPR, and the decision for or against life support may be easy. For other people, this decision is extremely difficult. The individual may want to have a say in this decision, or may simply want to follow the doctor’s recommendation. Either way, the information in the link below will help people understand what their choices are so that they can speak frankly with their health team about what is best for them. Get the Facts about CPR and Life Support

Making Decisions about receiving artificial hydration and nutrition

Many family members often feel concern when their loved one is no longer able to take food or fluids by mouth. This is usually a normal and natural slowing of the body’s functions, and hunger and thirst will ease away. Talk with your physician and health care team about this important topic. Choices about artificial hydration and nutrition
Navigating the System: Care Services at the End of Life

Navigating one’s way through the health care system is often very difficult, even for Health Care Professionals.

This part of the journey can be challenging and, at times, overwhelming.

This part of the palliative journey describes the places where people nearing end of life, family and care partners interact with the formal care system, government legislation, and other support services. Understanding the array of services that is available in the local community will assist in making best and preferred choices.

"Remember that death is a social event with a medical component, not a medical event with a social component. The larger part of dying happens outside of the institution and professional care".

Dr. Allen Kellehear
4th International Public Health and Palliative Care Conference 2015

Palliative Care: Easing the Journey with Care, Comfort and Choices

This resource provides an introduction to palliative care for patients, families, caregivers, health care teams and communities. Most of the stories and illustrations in this booklet are taken from experiences of First Nations people. However the palliative care message of comfort and choices applies to all patients and families throughout the world.

Easing the Journey

What is home-based palliative care?

Home-based palliative care is care provided by nurses, care aides, social workers and rehabilitation therapists in people’s homes.

People who receive home-based palliative services are individuals who:

- have been diagnosed with a life limiting illness and a life expectancy of six months or less;

- understand the philosophy of palliative care and are willing to accept and participate with this supportive approach to care;

- understand the terminal nature of their illness and agree that resuscitation is not appropriate, have a MOST or provincial No CPR directive signed by the doctor;

- are registered with the BC Palliative Care Benefits
What Services Does BC Palliative Care Benefits include?
The BC Palliative Care Benefits supports individuals of any age who are reaching the final six months or less of a life-threatening disease or illness, and who wish to receive palliative care at home. These provincial benefits provide medications, medical equipment and supplies, and home support services without charge while a person's condition remains palliative. A different program covers these needs if a person recovers and stabilizes, and may require the individual to then pay for some services. This policy assures that the benefits and resources will be there for those who need it most at end of life.

BC Palliative Care Benefits Patient Information Sheet

Who provides palliative care services at home?
The professional health services for people in their homes are primarily provided by nurses, occupational therapists or physiotherapists, and social workers. Personal care is provided by community health workers. In some areas, doctors still make home visits. Volunteers (e.g., Hospice Society or from a church or other group), spiritual leaders and friends and neighbours may help contribute to supporting a person who chooses to live out their final days at home.

What types of Home-based Palliative Health Services can be expected?
The health professionals will regularly assess the person's care needs as they change. They will work together to manage pain and other symptoms, provide emotional and spiritual support, and oversee all parts of the care provided in the home to meet the unique needs of the person and family.

Other services that they may provide include teaching family and caregivers how to give direct physical care (e.g., bathing, turning, mouth care, managing incontinence, etc.), prescribing medical equipment and supplies that make caregiving easier (e.g., beds, lifts, etc.), and organizing someone to come into the home so the caregiver may have a break (respite). Community health workers can provide basic personal care, medication and help with meals for the person. Volunteers and other community members may provide psychological, emotional and spiritual care and connection for both the individual and the family.

The days and hours of professional health services vary by community across Interior Health, and are supplemented with the provincial After Hours Palliative Nursing Service (see below).

Palliative and End of Life Care in Interior Health
Receiving Hospice Palliative Care Services
What is the After Hours Palliative Nursing Service?
The After Hours Palliative Nursing Service is a specialized provincial nursing program that provides toll-free after hours telephone support with advanced practice palliative nurses only between the hours of 9pm to 8am Pacific Time, every day of the year.

A brochure will be provided to individuals and families who are eligible to access the service by their home based palliative nurse. It is available in English, French, Punjabi and Chinese from your community health professional.

Hospice Societies
There are many hospice societies listed throughout Interior Health. It is never too early to contact hospice for information, education and support. See a listing of all Hospice Societies in Interior Health or check the BC Hospice Palliative Care Association (BCHPCA) website for member hospices.

BCHPCA Hospice Societies in IH

Planned/Expected Deaths: Options and Choices to Consider
Discussing and deciding where one wants to die is a very challenging and difficult thing to do with loved ones. In British Columbia, one may choose where to die including at home or in a Community Hospice Bed. These types of beds can be located in a free standing hospice facility (if available), or in a special palliative room within the local residential care facility. Hospitals are reserved for brief admissions to assist with pain and symptom management, with a plan to then go back home or to an alternate site such as a Community Hospice Bed. In some situations, and when there are no other options available to the individual, a person may die in hospital to remain in their home community.

Where to Receive Care
Deciding where to receive care as illness progresses can be challenging, but planning now for that care can decrease anxiety later on. The individual is encouraged to talk with loved ones about the type of care they would like to receive at the end of life. Discuss their expectations as well as individual wishes, care needs, finances, and the needs of the family. Choices may change as illness changes and advances.

Choosing Care Options

Considerations of a Home Death
Many Canadians say they would like to die at home, probably because home feels comfortable and familiar. Yet, most Canadians are not aware of what supporting a death at home might involve. The purpose of this article is to outline some of the potential challenges and rewards that come with a home death. That way, both individuals and caregivers can have a more realistic idea of what might be expected in this choice.

Considerations for a Home Death

Planning a home death in BC
In BC, an expected home death requires some planning and conversation with the doctor. In this province there is no legal requirement for the doctor or nurse to come to your home at the time of death.
However, forms signed by the doctor are needed to communicate appropriately with the Funeral Home or the BC Ambulance Service.

- **Notification of Expected Death in the Home** (to be completed by the doctor)

- **Patient and Family Instructions if you want to die naturally at home** (see page 2)

**Caregiving Supports**

Caregiving can be both a rewarding and challenging experience. When caregiving goes on for a long period of time, or when there are specific challenges in providing care, a caregiver may feel taxed and stressed. Feeling frustrated and upset can have serious consequences for both the caregiver, the person they are caring for and other family members, and is an important sign that it is time to seek help.

Learning some new strategies in caring for the person and in caring for self is a useful approach to combatting stress. The home-based palliative nurse can teach family and caregivers useful approaches and techniques to give care and make practical suggestions to address any concerns.

**Taking Care of You**

Take time to explore these caregiver self-care strategies for everyday living.

- **Self Assessment, Reflection and Self Care** (Victoria Hospice)

**Providing Everyday Care**

The essential step-by-step practical instructions in how to provide physical care for someone who can no longer help his or her self is available at the link below. Topics include: bathing, giving medications, care for hair, skin and mouth, preventing bed sores, eating, toileting and sleep.

- **Providing daily care**

**Communication**

Whether it is talking with the doctor or health care providers, visitors or the person who is dying, end of life care is about effective communication.

- **Tips for Talking**

**Managing Pain**

Pain and other symptoms related to life-limiting illness can almost always be managed effectively. Talk to the doctor and community health professionals about any symptom of concern.

- **Pain Control at the End of Life**
Managing Other Common Symptoms

- Confusion
- Shortness of Breath
- Constipation
- Nausea and Vomiting
- Sleep Disturbance
- Fatigue

The Final Days
As a person enters the final stage of life, it can be a period of distress and emotions for all involved. The person and their family members might be too upset to think or talk about things, and both may try to “protect” the other by avoiding challenging conversations. However, having these crucial conversations and having planned ahead, can lead to a better death experience (a “good death”). Health care professionals can participate and assist the person and family in these types of conversations if desired, as the final days and hours draw nearer.

When death is near
In the final phase of progressive life-limiting illness, patients and families face changes, challenges and choices that are unfamiliar and can seem overwhelming. Learn what might be expected as death nears.

When Death is Near

The final hours
Both the person who is dying and those who care for him or her may have questions and concerns about what will happen physically and emotionally in the final hours of life. The following information may help answer some of these questions.

Description of the Dying Process

Rituals to Comfort Families
Simple acts of caring are in themselves rituals. In difficult times, these ritualistic acts may take on extra significance. They can become ways of ordering and calming the feelings that arise. Rituals can be a source of comfort for the family, caregiver and the one who is dying.

Rituals for Comfort
Immediately Following Death

When an expected death finally occurs after a long illness, it can still be a surprise and seem surreal. It is common to have intense emotional reactions when someone dies, even if family and caregivers were expecting the death and thought they were prepared.

The Moments after a Death

Traditional Approaches to Death and After Death Care

Care of the Body After Death
Organizing a Funeral
Death Care Services in BC

Alternative Approaches to Death and After Death Care

Planning a Home Funeral

Canadian Integrative Network for Death Education and Alternatives (CINDEA)
CINDEA provides information and resources about alternative ideas regarding the time before, during & after a death occurs. Topics such as advanced care planning, funeral homes, “green” burial options, and others are discussed here.
After Death: Grief and Bereavement
Grief support for the family and caregivers following death is an essential part of care for the dying.

Grief and Grieving – An overview to the topic

Grief Work

Coping with Grief

Grieving and Treatment
Grief itself is a natural response that doesn’t require medical treatment. But sometimes people need help getting through the grieving process.

Grief in Times of Celebration – The Empty Spot

BC Bereavement Help Line - 1-877-779-2223
(free, confidential and anonymous support)

Acknowledgements

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- Health Link BC: www.healthlinkbc.ca
- BC Cancer Agency: http://www.bccancer.bc.ca/
- BC Hospice Palliative Care Association: http://bchpca.org/
- Victoria Hospice Society: http://www.victoriahospice.org/
- BC Funeral Association: http://www.bcfunerals.com/about-bc-funeral-association/overview

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