Palliative Journey Resource Guide

This guide offers resources to individuals, and their families and caregivers, to support their care needs during advancing illness and planning for end of life care.

August 2023

Interior Health

"We cannot change the outcome, but we can affect the journey."

- *Ann Richardson, Hospice Volunteer*

Palliative and End of Life Care Information and Resources for Individuals, Families and Caregivers

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What is Palliative Care?

Palliative care is a holistic approach that provides treatment and care for individuals, and their families, who are living with an advancing life-limiting illness. Palliative care relieves symptom distress and improves the quality of life for persons who are coping and living with an advancing life-limiting illness, as well as for those who are bereaved. (Canadian Hospice Palliative Care Association).

The goals of palliative care are to ease a variety of physical and emotional symptoms, to support and enhance quality of life, and to inquire and ensure a person's wishes will guide the care provided by the health care team, 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 is timely information and education about the palliative care journey.

This resource guide is a list of online resources 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. The content in this guide is not considered an exhaustive list.

This document has purposefully been divided into major sections that follow the different stages that a person with advancing illness will likely experience.

The sections include:

- Describing the Palliative Journey:
    - Cancer illnesses
    - Chronic diseases and other illnesses
- The Importance of Seeking Support
- Expressing Your Wishes
- 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

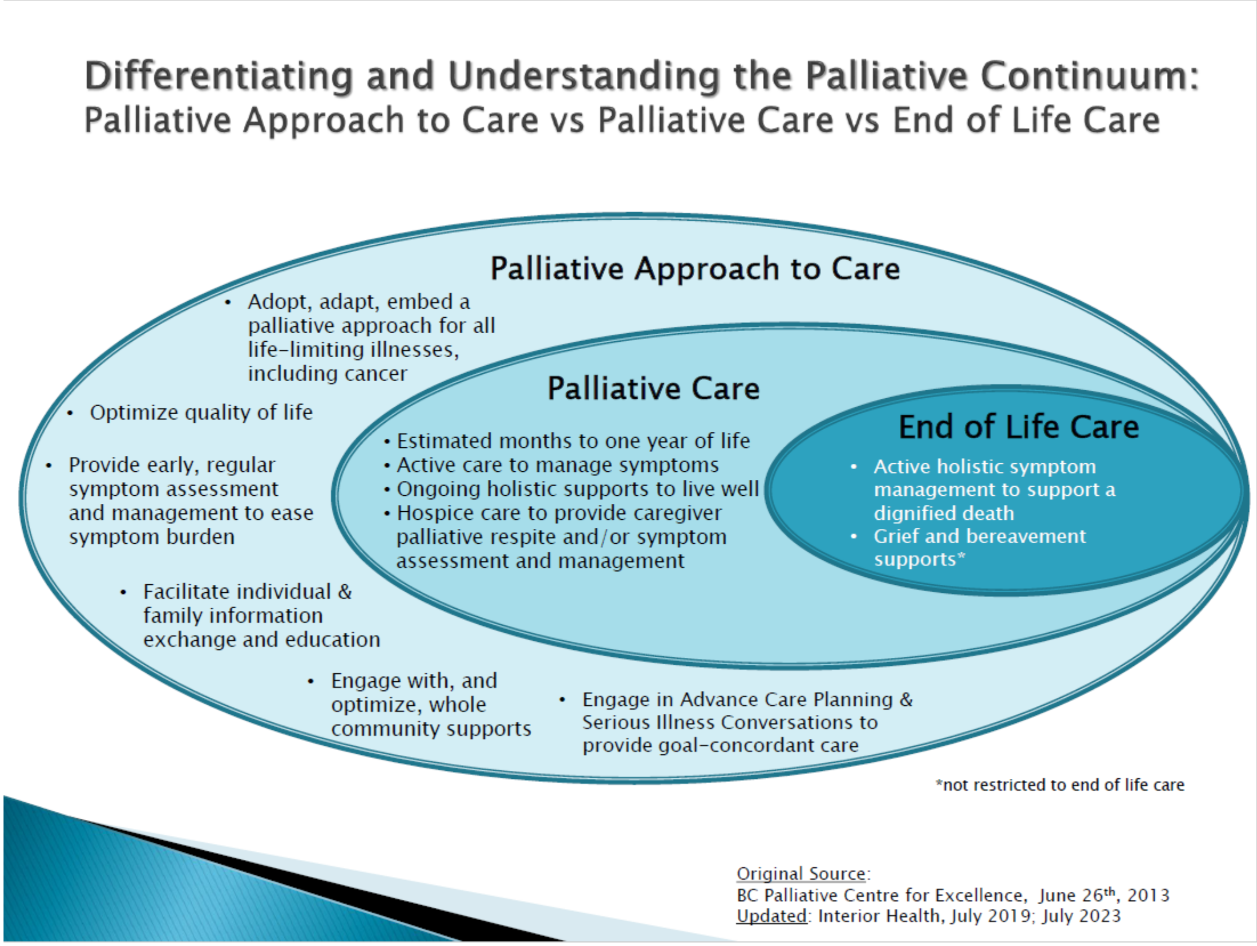
This resource is meant to be used electronically to be able to access the links to the various documents, videos and websites. If you do not own a personal computer you may be able to access one at your local public library, or ask a friend or family member to assist you.

For additional information please visit the Palliative and End of Life Care page on Interior Health's public website.

Describing the Palliative Journey

Palliative care is person-centred, coordinated care that aims to relieve suffering and improve quality of life at *all stages* of a life-limiting illness.

Palliative care is a holistic approach that treats the clinical, emotional and spiritual needs of individuals and their families; it focuses on comfort and support, assists with making plans and decisions for the journey ahead, and optimizes quality of life.



Differentiating and Understanding the Palliative Continuum:
Palliative Approach to Care vs Palliative Care vs End of Life Care

Palliative Approach to Care

- Adopt, adapt, embed a palliative approach for all life-limiting illnesses, including cancer
- Optimize quality of life
- Provide early, regular symptom assessment and management to ease symptom burden
- Facilitate individual & family information exchange and education
- Engage with, and optimize, whole community supports
- Engage in Advance Care Planning & Serious Illness Conversations to provide goal-concordant care

Palliative Care

- Estimated months to one year of life
- Active care to manage symptoms
- Ongoing holistic supports to live well
- Hospice care to provide caregiver palliative respite and/or symptom assessment and management

End of Life Care

- Active holistic symptom management to support a dignified death
- Grief and bereavement supports*

*not restricted to end of life care

Original Source:
BC Palliative Centre for Excellence, June 26th, 2013
Updated: Interior Health, July 2019; July 2023

The palliative journey is a continuum. The timeline can vary depending upon the nature of the illness. Generally, there are three phases: Palliative Approach to Care, Palliative Care, and End of Life Care.

Sharing health care wishes and goals with loved ones, doctors, nurse practitioners and other health care providers is important. Having an Advance Care Plan ensures your wishes are known and will be followed by your loved ones and health care providers. Resources can be found on Interior Health's Advance Care Planning webpage.

What do you Understand about Palliative Care?

Many people are uncomfortable or distressed when they hear the term ‘palliative care’ believing it to mean death and dying. However, the true meaning of ‘palliative’ is to ease symptoms and help people live well for however much time they have. Below are 10 common myths and misunderstandings about palliative care prepared by Canadian Virtual Hospice.

This fact sheet is also available in 12 other languages: [10 Myths About Palliative Care Infographic (virtualhospice.ca)]

CANADIAN VirtualHospice

10 Myths about Palliative Care

Palliative care is still misunderstood. Here are 10 common myths we often encounter. Help dispel these myths by sharing the facts with family members and friends, colleagues, patients, and clients.

Myth 1: Palliative care makes death occur sooner.

Fact: Palliative care does not make death occur sooner. It helps improve comfort and quality of life from diagnosis until death.

Myth 2: Palliative care is only for people dying of cancer.

Fact: Palliative care can benefit people who have been diagnosed with any illness that may shorten life. Palliative care can also benefit their families and friends.

Myth 3: People in palliative care who stop eating die of starvation.

Fact: People with advanced illnesses often don't experience hunger or thirst as healthy people do. People who stop eating die of their illness, not of starvation.

Myth 4: Palliative care is only provided in a hospital.

Fact: People can receive palliative care in a variety of locations, including at home, in a long-term care facility, in a hospice, or in a hospital.

Myth 5: We need to protect children from being exposed to death and dying.

Fact: Talking with children early on in someone's illness, and providing honest and clear information that is age appropriate, is the best way to protect them. Like adults, children also benefit from having time to say goodbye to people who are important to them.

Myth 6: Pain is a part of dying.

Fact: Pain is not always a part of dying. If pain is experienced near end of life, there are many ways it can be addressed.

Myth 7: Taking pain medications in palliative care, leads to addiction.

Fact: Keeping people comfortable often requires increased doses of pain medication as the body gets used to the medication. It is not addiction.

Myth 8: Morphine makes death happen faster.

Fact: Morphine, or medication similar to it, is used to help keep patients comfortable. In proper doses, morphine does not make death happen sooner.

Myth 9: Palliative care means the patient's doctor has given up and there is no hope.

Fact: Palliative care providers help people achieve their best quality of life, for the rest of their life. Hope changes from curing the disease, to living life as fully as possible.

Myth 10: If my family member or friend doesn't die at home, I'm letting them down.

Fact: Sometimes a person's needs cannot be met at home despite the best efforts. Ensuring that the best care is delivered, regardless of setting, is not a failure.

virtualhospice.ca

Available in French, Arabic, Brazilian Portuguese, Catalonia, Chinese, Cree, Hebrew, Inuinnaqtun, Italian, Japanese, Portuguese, Spanish, and Tagalog

For some people, the journey begins with an unexpected diagnosis of cancer for which there may be no cure. Others may live for years with cancer or other chronic diseases that effect the heart, lungs, kidneys or brain, making daily living increasingly difficult.

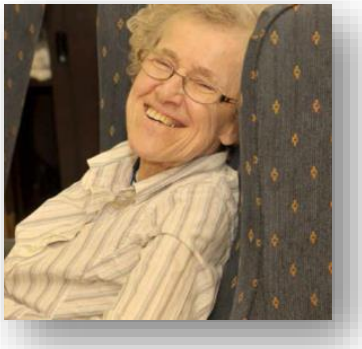
The Cancer Palliative Journey

The palliative journey for people living with cancer often begins when they are first told by their doctor of their diagnosis. A palliative approach is valuable throughout the cancer journey in managing and easing emotional and physical symptoms during cancer treatments.

Over time, conversations shift and may include reviewing advance care plans, talking about preferences and choices for what is most important to the person, how they wish to live with however much time remains, 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 symptoms and identify which treatment and medication options may continue, but with the focus now being on comfort rather than the purposes of a 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 and their families throughout the cancer journey.



The Non-Cancer Palliative Journey

The number of adults living with advancing chronic illness is increasing as we live longer lives. Older adults are at greater risk for illnesses such as congestive heart failure, chronic obstructive lung disease, kidney disease, Alzheimer's disease or other types of dementia illnesses. All people living with advancing chronic illness would benefit from a palliative approach to care to ease symptoms and improve quality of life.

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. Timely, end of life planning is an important part of good care for individuals and families. This Resource Guide provides information to support people on this journey.

The Importance of Seeking Support

People living with advancing illness, family members and caregivers all require support. 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 person 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 who 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 to 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

BC Cancer's (BCC) counselling staff have created a library of patient handouts on topics such as anxiety, coping with anger, deep breathing exercises and muscle relaxation, strategies to manage stress and improve sleep, as well as relaxation CDs, e-books and other resources.
BCC Patient handouts to cope with treatment and beyond
Relaxation CDs and other resources in the BC Cancer Library

Considering Spiritual Health Issues

A life-limiting illness can raise questions about life's meaning and purpose. It may cause a person to reflect upon their life and spiritual needs. Even when someone 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

Expressing Your Wishes

It is important to express the type of care you prefer, and your wishes, to loved ones and health care professionals as your health continues to change. It can be hard to think about one's own death; many thoughts and emotions may surface, yet it is something that we must all face one day.
Considering Hospice Palliative Care

Advance Care Planning – My Voice Planning Guide
Advance care planning is making an plan for future health care in case you are unable to speak for yourself due to an unexpected health care event. Have early discussions with loved ones and health care professionals about the kinds of care that are or are not preferred, including conversations to continue or decline life-support measures. Don't assume that family and health care professionals know what you want. My Voice Planning Guide – Expressing my wishes for future health care treatment

what matters MOST
Talk Early / Talk Often

Medical Orders for Scope of Treatment (MOST)
MOST is a physician or nurse practitioner order that tells health care providers what treatment is preferred. To better prepare for future treatment options, talk with your doctor, nurse practitioner and health care team to better understand your 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 be provided to the person by the doctor or nurse practitioner and can be kept in the home on the side of the fridge in a Greensleeve, which is the most common spot where visiting health professionals will look.
Learn more about MOST and Advance Care Planning

Making Decisions about Receiving Cardiopulmonary Resuscitation (CPR) and Life Support
Talk with your doctor or nurse practitioner about advancing illness, specific treatment options regarding CPR and life support, and chances for recovery. Including family in these conversations can be helpful to clearly state end of life wishes and preferences.
Learn more 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 health care professional about this important topic.
Learn more about artificial hydration and nutrition

Navigating the System: Care Services at the End of Life

Navigating one’s way through the health care system can be very difficult, even for health care professionals, and can feel 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 are 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

What is home-based palliative care?
Home-based palliative care is 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 an advancing, life-limiting (cancer or non-cancer) illness, and have a life expectancy of approximately six months to one year
- understand the nature of the life-limiting illness and consent to the focus of treatment being to support symptom management and quality of life rather than aimed at a cure
- have a MOST with an M designation signed by their doctor or nurse practitioner
- are registered with the BC Palliative Care Benefits (see link below).

What services do the BC Palliative Care Benefits include?

BC Palliative Care Benefits cover the cost of certain medications, palliative supplies and equipment, and home support services. These benefits are available to individuals (of any age) who have reached an estimated last six months of a life-limiting illness or disease, and who wish to receive palliative care in their home.

This provincial program assures that the benefits and resources will be there for those who need it most to support end of life care at home. If a person recovers through treatment and no longer meets the palliative criteria, home health services can still be provided based on the needs of the individual but may require the individual to then pay for services, depending on income levels.
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, physiotherapists, and social workers. Personal care is provided by community health workers. In some areas, doctors and nurse practitioners may make home visits. Volunteers (e.g., Hospice Society, a church or other group), spiritual leaders, friends and neighbours may help contribute to supporting a person and their family who choose to die at home.

What types of home-based palliative care services can be expected?

The health professionals will regularly assess the person's care needs as they change. They will work together to monitor and manage symptom burden, provide emotional 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.
Receiving Hospice Palliative Care Services

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.

The **After Hours Palliative Nursing Service** is a provincial nursing program that provides toll-free after hours telephone support with advanced practice palliative nurses *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 within the Interior Health region

Hospice societies provide a range of services for individuals, families and communities. It is never too early to contact your local hospice society for information, education and support. Communities are fortunate to have many Hospice Societies within Interior Health. You can also check the BC Hospice Palliative Care Association (BCHPCA) website for member hospices.
BCHPCA List of Hospice Providers

Planned/Expected Deaths: Options and Choices to Consider

Discussing and deciding where one wants to die can be challenging and difficult. In BC, a person may choose where to die including at home or in a Community Hospice Bed (CHB) located in a free-standing hospice (if available) or in a special palliative room within a local long-term care facility. Hospitals are preferably used to assist with symptom management followed by a return home or to a CHB. There may be situations when an individual needs to remain in hospital for their end of life care.

Where to Receive Care

Deciding where to receive care as illness progresses can be challenging, but planning for that care earlier can decrease anxiety later on. The person 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, yet most Canadians are not aware of what supporting a death at home might involve. Canadian Virtual Hospice outlines some of the potential challenges and rewards that come with a home-based death so both individuals and caregivers can have a more realistic idea of what might be expected with 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 or nurse practitioner. 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 medical practitioner 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 or nurse practitioner)
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 occurs for a long period of time, or if there are specific challenges in providing care, a caregiver may feel tired and stressed which can have serious consequences for both the caregiver, the person they are caring for and other family members. It is an important sign that it is time to seek help.

Learning some new strategies in caring for the person and in caring for oneself is a useful approach to coping with 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

You and your health is important. Take time to explore these caregiver self-care strategies for everyday living.

Self Assessment, Reflection and Self Care

Providing Everyday Care

The essential, step-by-step practical instructions in how to provide physical care for someone who can no longer help themselves 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, nurse practitioner, other 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 advancing illness can almost always be managed effectively. Talk to the doctor, nurse practitioner and community health professionals about any symptoms 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 many 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 planning ahead as much as possible 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 near.

When Death Nears
In the final phase of a progressive illness, individuals and families face changes, challenges and choices that may be unfamiliar and overwhelming. Learn what might be expected as death nears.
Tips for Talking with Someone Who is Dying

The Final Hours
Both the person who is dying and those who care for them 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.
Final Weeks and Days: What to expect

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

Living My Culture
Quality palliative care embraces and honours a person's culture, spirituality and traditions. At LivingMyCulture.ca people from various cultures share their stories and wisdom about living with serious illness, end of life and grief, to support others.

Immediately Following Death

When an expected death occurs after a long illness, it can still be a surprise and seem surreal.

It is common to have deeply emotional responses 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

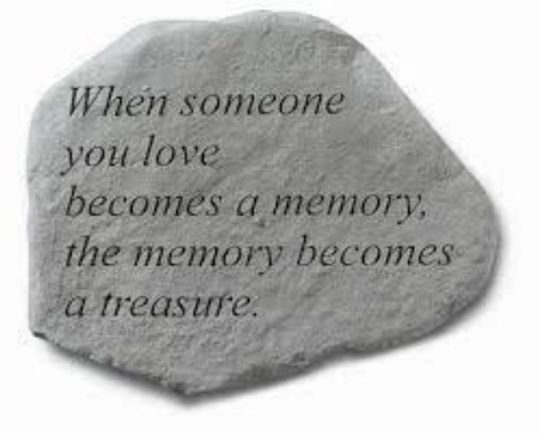
Alternative Approaches to Death and After Death Care

Planning a Home Funeral

Canadian Integrative Network for Death Education and Alternatives (CINDEA)
CINDEA is a Canadian-based organization that provides information and resources about alternative ideas regarding the time before, during & after a death occurs. Topics such as advance care planning, funeral homes, “green” burial options, and others are discussed here.

After Death: Grief and Bereavement

Grief support for family and caregivers following a death is an essential part of care for the dying.



Grief and Grieving

Grief Work

Coping with Grief

Helping Children with Grief

Helping Teens with Grief

Helping Older Adults with Grief

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

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