

RESOURCE GUIDE

HOSPICE PALLIATIVE CARE IN THE BOW VALLEY

Prepared by the PCSBV Resource Guide Team August, 2018

If you are not sure where to start,

START by calling Bow Valley Home Care (A.K.A Community Care.
The names are used interchangeably) at 403-678-7200. The staff will help you navigate what you should do first, based on your particular circumstances. Otherwise, start with the Section that best meets your needs at this time.

"Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it's the only thing that ever has."

Margaret Mead

We welcome your feedback on this inaugural edition of the resource guide! Please email your comments to bjprice@shaw.ca

If you would like a hard copy of this resource guide, please call 403 707 7111.

TABLE OF CONTENTS

SECTION	PAGE
 INTRODUCTION	01
Definition of Disease Management • How to Talk to My Doctor Octors' Offices in the Bow Valley • MAiD	09
2. PHYSICAL CARE AND SUPPORT • Physical Changes • Who Should I Talk To • Symptoms • Bow Valley Resources	17
SOCIAL SERVICES AND SUPPORT • Talking With My Children & Grandchildren • Conversations With My Family • Coping Strategies • Community Services and Support • Caregiver Support	23
4. SPIRITUAL CARE AND SUPPORT • Meaning of Spirituality • Pastoral Care Resources in the Bow Valley • Palliative Volunteers • Mindfulness Meditation • The Role of Nature • Other Bow Valley Resources	29
 5. END-OF-LIFE CARE AND DEATH MANAGEMENT Personal Directive • Goals of Care • Power of Attorney • Will • Advance Care Plan Legacy • Dying at Home • Planning Your Funeral • Final Days • MAiD 	35
6. LOSS AND GRIEF • How Grief Works • Who Can I Talk To • Other Resources (Internet, Social Media, Radio, Boo	41 oks)
7. COMMUNITY SERVICES AND SUPPORT • Nursing Care • Medical Supplies • Transportation • Palliative Volunteers • FCSS • Respite • Caregiver Support • Community Supports • Regional, Provincial & National Supports	47
8. ADMINISTRATION OF DYING • Financial Assistance at the End of Life • Financial Assistance for Caregivers • Personal Directive and Power of Attorney • "I'm Dead: Now What?" • Funeral and Legal Services	53
9. INVENTORY OF HOSPICE PALLIATIVE RESOURCES, FIRST NATIONS, MORLEY • First Nations peoples may also access many of the above resources.	61
THE BOOK OF LINKS	65
BOOK AND MUSIC LIST	71
INTERPROFESSIONAL EDUCATION AND LEARNING	75
CALGARY HOSPICES AND RESOURCES	79





If you are not sure where to start,

START by calling Bow Valley Home Care (A.K.A Community Care.

The names are used interchangeably) at 403-678-7200. The staff will help you navigate what you should do first, based on your particular circumstances. Otherwise, start with the Section that best meets your needs at this time.

WHAT IS THE PURPOSE OF THIS GUIDE?

If you, or someone you love of any age, have a terminal illness, you may find yourself navigating an entirely new world of specialists, referrals, test results, treatments, medications and difficult decisions. Being ill is hard enough, without having to learn the ins and outs of the health care system at the same time. The purpose of this guide is to help you plan in advance of a terminal illness, and to navigate the unsettled waters of hospice palliative care in a complex heath care system. We want you to know what help is available to you and that you are not alone.

We recognize that many people in our rural Bow Valley Communities need information on hospice palliative care and how to access community and regional resources. This guide is an "inventory" of such resources in the Bow Valley. It has been prepared especially for you, your family and other loved ones using what we have learned from regular folks in our Bow Valley communities, health professionals and volunteers of the Palliative Care Society of the Bow Valley.

There is a lot of information in this Guide. Focus on the Sections that are relevant to you, rather than reading all the Sections, one after the other. Other Sections can be read later.

Please note: Stoney Nakoda First Nation peoples from the Morley Reserve may access the Bow Valley resources included in the first eight Sections of this Guide. Otherwise, the local Town of Morley resources are identified on a table is **Section 9. Inventory of Hospice Palliative Resources**, **First Nations**, **Morley** on page 61.

WHO WILL USE THIS GUIDE?

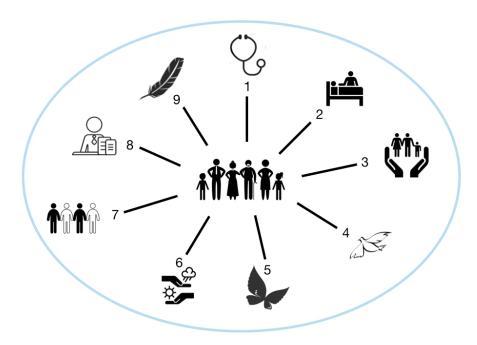
This guide is for those who want to plan their health care in advance and those who have been diagnosed with a terminal illness, which may include: advanced cancer, heart disease, lung disease, kidney disease; and terminal neurological diagnoses such as Lou Gehrig's Disease (ALS). Family members, friends, health care providers and others may also find it useful.

W HOW IS THIS GUIDE ORGANIZED?

The model shown on the next page accurately defines the aspects that will be covered, when identifying hospice palliative care community resources in our communities. At the centre are the Patient and Family, who are affected by any, or all, of the issues shown. No subject stands alone; there is some overlap and cross referencing to other Sections.

The model's intent is also to show holistic, or intimately connected, aspects of your care. It takes into account mental and social factors, and not just physical symptoms of your illness.

CHPCA = Canadian Hospice Palliative Care Association CHPCA Aspects Associated with Terminal Illnesses and Bereavement



1. DISEASE MANAGEMENT

means working with your doctor to determine the best course of action to manage your illness.

2. PHYSICAL CARE AND SUPPORT

means working with your health care team to manage your physical symptoms that arise as you progress through palliative care, such as pain, and mobility and nutrition issues.

3. SOCIAL SERVICES AND SUPPORT

means our cultural response to dying, including values, beliefs, and our relationships with family, friends and community. Questions arise such as, "What should I say about this? Who can I talk to? Where can I go to get help?"

4. SPIRITUAL CARE AND SUPPORT

means exploring spiritual meaning in times of terminal illness. It is reflecting on how such illness has changed your life, family and community. Community resources are available to provide compassion and guidance.

5. END-OF-LIFE CARE (AND DEATH MANAGEMENT)

means how you want to say goodbye. It involves gift giving, rites and rituals, funeral preparations and life closure activities.

6. LOSS AND GRIEF

means learning to share your sadness about your condition with those you love and others you care about. It means grief is a highly personal response and takes its own path.

7. COMMUNITY SUPPORT

means those supports, provided by local and regional programs and businesses, which are practical in nature.

8. ADMINISTRATION OF DYING

means the management of your legal, financial and funeral affairs. It includes a focus on your expenses and what resources are available to help you.

9. INVENTORY OF RESOURCES, STONEY NAKODA FIRST NATIONS, MORLEY

means hospice palliative resources located locally in the Town of Morley on the reserve.



WHAT IS HOSPICE PALLIATIVE CARE?

Hospice palliative care is whole-person care that aims to relieve suffering and improve the quality of living and dying. It addresses physical, psychological, social, spiritual and practical issues, and associated expectations, needs, hopes and fears. Remember, hospice care, commonly referred to as end-of-life care, is only a part of palliative care.

Hospice palliative care helps people, who have been diagnosed with a terminal illness, live out their remaining time in comfort and dignity. It is helpful not only when a person is approaching death, but also at earlier stages of an illness. It can also help families meet the challenges they face when a loved one's illness cannot be cured.

When facing the threat of death, you have to make a painful transition, from thinking of yourself as "somebody who might die", to "someone who will die". The transition consists of many stages and it is difficult no matter what your age and the nature of your illness. Phases include:

- The beginning, or early, phase as you face the threat of death
- An illness phase, in which your pattern of living becomes altered by physical decline
- The final phase, in which you are approaching death

The image below illustrates the transition from the beginning phase, to the final phase and beyond. It has been prepared by the CHPCA and adopted across Canada to help people understand the terminal illness progression.

Focus of Care Therapy to modify disease Hospice Palliative Care Therapy to relieve suffering and/ or improve quality of life Presentation/ Diagnosis Illness Acute Chronic Advanced Life-Threatening End-Of-Life Care

CHPCA Model for the Role of Hospice Palliative Care During Illness

Starting on the left, palliative care is introduced early, when a diagnosis of terminal illness is made. Treatment to modify the original disease is often provided hand-in-hand with palliative care. As you travel across the image, you see that less and less disease treatments are provided, while more and more hospice palliative care is provided, right to end-of-life care. At the far right of the illustration, you see Bereavement, which is grief support provided to families and others, after a person's death.

WHAT IS AN INTEGRATED PALLIATIVE APPROACH TO CARE?

In urban centres, palliative care is a specialty. The difference in rural communities is that palliative care is a part of a health care team's every day practice (nurses, doctors, psychologists, occupational & physical therapists etc.) An integrated palliative approach makes key aspects of palliative care available to individuals and families during a terminal illness and in all care settings. (For more, see The Book of Links).

"When people have access to hospice palliative care services integrated with their other care, they report fewer symptoms, better quality of life, and greater satisfaction with their care. The health care system reports more appropriate referrals, better use of hospice care, fewer emergency room visits and hospitalizations, and less use of ineffective, intensive interventions in the last days of life."

(CHPCA, The Way Forward, 2015, page13)

♥ WHERE DO I GO TO RECEIVE HOSPICE PALLIATIVE CARE?

Hospice palliative care can be delivered in many care settings. These include your own home, a lodge, in the Emergency department or the acute care unit of your local hospital, or in a long-term care facility. You and your family will decide where the best place is for you to receive care, and it will change over time, depending on your circumstances. You and your family are in charge of where you go. In the next Section, you will meet some of the care providers who will look after you in these various settings.

MEET YOUR TEAM

You are not alone on this journey and your health care team will help you. Your caregivers plan the best hospice palliative care based on your needs. They will:

- Learn about your particular needs
- Meet with you and your caregivers to talk about your options
- Prepare for the place you will receive care

Please talk to anyone on your team about any issues that are important to you. You may have many questions or concerns about many topics such as:

- Your symptoms
- What you and your caregivers expect for your future
- Your hopes and fears
- Your future planning
- Grief and bereavement

Your team will make sure your concerns are addressed. If they are not effectively addressed, you should be confident in asking for solutions (see **Section 1. Disease Management**, pages 9-14). Continuity of care and follow-up are as important as treatment of your symptoms.

Doctor and Nurse

Your doctor or nurse will work with you and others to help control any symptoms that cause you discomfort or distress. They can also help with:

- Supporting you and your caregivers through your illness
- Discussing and helping you decide the best care for you, by reviewing your Goals of Care (GOC)
- Informing you about and helping you with Advance Care Planning (ACP).
 Read more about this in Section 1. Disease Management and Section 2. Physical Care & Support
- Finding hospice palliative care resources in our communities
- Adjusting from hospital care, to home care

Nurses, which may include Registered Nurses (RNs), Licensed Practical Nurses (LPNs), or Personal Care Aides (PCAs), provide regular assessments and care. They are familiar with your medical needs and help you with many daily tasks such as:

- Helping to take medications
- Changing bandages and cleaning wounds
- Recovering from an injury or health problem
- Checking your overall health
- · Creating a patient-centered care plan
- Checking and managing your pain



You may want to discuss a referral, with your nurse or doctor, to the Alberta Health Services (AHS) Rural Palliative Consultation Team from the Calgary Zone. They are a team of specialized nurses and doctors who provide consultative support to rural primary care nurses and doctors outside the Calgary city limits. Their goal is to improve palliative care and quality of life for people with a terminal illness.

Counsellors

Counsellors, such as social workers, financial advisors and psychologists, help you and your caregivers cope with the impact of your illness. They are there to help you with many types of needs. These include emotional, financial and any practical needs. They can give you:

- Individual and family counselling about coping with illness, loss and grief
- Information about practical and financial resources
- Information about hospice palliative care resources in our communities
- Support with transitions from home to hospital and back again
- Organizing family meetings with your health care team
- Information about Advance Care Planning

Physical and Occupational Therapists

These therapists will check to see how well and how safely you move around and function. They also check to see how you manage your daily activities. This includes getting dressed and taking a bath. They may also recommend equipment to help you such as:

- Wheelchairs and walkers
- Bedside commodes
- Hospital beds
- Bath chairs

Spiritual Care

Spiritual care providers are there to help you find what you need and what is important to you. You do not need to belong to any specific religion to receive support. Spiritual care includes:

- Exploring spiritual meaning in times of illness
- Reflecting on how illness has changed your life, family and community
- Providing encouragement and support
- · Providing support for loss and grief
- Providing a time for prayer, meditation and reflection

Dietitian

Dietitians help you with nutritional needs due to your illness. They will make recommendations to help you keep the safest and most satisfying diet.

Respiratory Therapist

Respiratory therapists may check to see if you need oxygen at home. They will also help you learn about funding available for home oxygen.

Trained Palliative Volunteers

These volunteers provide compassionate companionship in many different ways and may be found in the Banff and Canmore hospitals, lodges, your homes, or long-term care facilities. They have special training provided by Alberta Health Services, and their work is coordinated by the Bow Valley Volunteer Coordinator located at the Canmore Hospital.

Write your questions, or notes, here. You might want to list the names and contact information of "your team".		





1. DISEASE MANAGEMENT

1. DISEASE MANAGEMENT



WHAT DOES DISEASE MANAGEMENT MEAN?

Let's suppose that you have just received news from your doctor that your cancer, or any illness, has progressed and, despite previous treatments, your disease is terminal. This scenario or something similar is perhaps what you may be facing right now. As the news of your diagnosis sinks in, questions you have, will emerge about your diagnosis: questions that need answers. Although you may feel you are the only person in the world facing this crisis, we want you to know that you are not alone.

WHAT NOW?

When you have received the diagnosis of a terminal illness, your life may dramatically change. In addition to the physical changes, you may experience a wide range of issues including:

- Having questions regarding the progression of symptoms of your disease
- Changes in your roles and relationships
- Loss of opportunity, income and financial security
- · Changes in traditional family dynamics

There are people and other resources in the Bow Valley that can offer you and your family support for your physical and emotional needs through an integrated approach to hospice palliative care.

WHAT IS HOSPICE PALLIATIVE CARE?

Hospice palliative care is whole-person care that aims to relieve suffering and improve the quality of living and dying. It addresses physical, psychological, social, spiritual and practical issues, and associated expectations, needs, hopes and fears.

WHAT WILL YOU FIND IN THIS SECTION?

This Section of the Resource Guide offers a list of several resources that you can access related to understanding the progression of your illness. It will also direct you to resources to better manage the symptoms associated with the progression of your illness and end-of-life care.

WHAT KINDS OF DISEASES REQUIRE HOSPICE PALLIATIVE CARE?

Most hospice palliative care focuses on cancer but other diseases include COPD, advanced heart, kidney and lung disease, and terminal neurological diseases, such as ALS.

WHERE CAN I FIND MORE INFORMATION ON THESE NON-CANCER DISEASES?

DISEASE	WEB SITE
ALS (Lou Gehrig's Disease)	www.alsab.ca www.als.ca
COPD	www.lung.ca/copd
Advanced Heart Disease	www.heart.org Follow links to "Living with Heart Failure"

The key to Disease Management lies in having a good understanding of the progression of your disease. Developing a patient-centred care plan, hand-in-hand with your care team, is very important. It will help meet the unique needs of you and your family.

HOW DO I TALK WITH MY DOCTOR ABOUT DISEASE MANAGEMENT?

1. Serious Illness Conversation Guide is a guide used by doctors when they have conversations with you about your illness and how it is managed. Referring to it will help you gain an understanding of your doctor's approach to helping you face your illness, learn what to expect going forward, and identify your health care goals.

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. Set up the conversationIntroduce purposePrepare for future decisionsAsk permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — <i>is this okay?</i> "
2. Assess understanding and preferences	"What is your <i>understanding</i> now of where you are with your illness?" "How much <i>information</i> about what is likely to be ahead with your illness would you like from me?"
 3. Share prognosis Share prognosis Frame as a "wishworry",	"I want to share with you <i>my understanding</i> of where things are with your illness" Uncertain: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility." OR Time: "I wish we were not in this situation, but I am worried that time may be as short as (express as a range, e.g. days to weeks, weeks to months, months to a year)." OR Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."
 4. Explore key topics Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family 	"What are your most important <i>goals</i> if your health situation worsens?" "What are your biggest <i>fears and worries</i> about the future with your health?" "What gives you <i>strength</i> as you think about the future with your illness?" "What <i>abilities</i> are so critical to your life that you can't imagine living without them?" "If you become sicker, <i>how much are you willing to go through</i> for the Possibility of gaining more time?" "How much does your <i>family</i> know about your priorities and wishes?"
 5. Close the conversation Summarize Make a recommendation Check in with patient Affirm commitment 	"I've heard you say that is really important to you. Keeping that in mind, and what we know about your illness, I <i>recommend</i> that we This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
Document your conversation Communicate with key clinicians	

- Focus of care is on you and your family and your needs
- Your responses may change with time, but the key is to keep the dialogue open and focused on your needs



2. What questions could I ask my doctor?

- What caused this illness?
- What should I expect to happen to me physically over the course of the illness?
- Will I be in pain?
- Will I become addicted to the pain medication?
- What does dying look like?
- Who will look after me when I can't do it myself?
- What are the risks of the treatment that I will be receiving?
- Is my illness terminal?
- How long do I have? Doctors may not have precise answers to this question and a general idea may be all that is possible.
- How can I manage the quality of my life and set my treatment goals?

3. What resources are available to help me talk to my doctor?

Virtual Hospice web site is an extensive web site with information and support on palliative and end-of-life care, loss and grief **www.virtualhospice.ca**.

Follow the "Support" link to:

- Ask a professional
- Asked and Answered
- Discussion
- Symptoms & Health Concerns

4. Other Disease Factors

Your present illness may be complicated by your previous state of health. These factors are called, in medical language, "co-morbidities" and may include conditions such as diabetes, and chronic diseases of the lungs, heart, kidneys, or nervous system.

You may also experience side effects from your drug therapy, including nausea and vomiting, fatigue, loss of appetite, or allergic reactions.

WHAT NOW?

- Conversation with your doctor, including your family members and caregivers, to gain an understanding of new symptoms and provide symptom relief. You may also want to ask what to expect, physically, going forward.
- Ongoing conversation with your doctor and nurses, to understand how you may react to options for treatments, and who to contact, if previously unexpected problems arise
- Discussion about the risks and benefits of therapies according to your goals of treatment

Here is something to keep in mind, expressed so well by a doctor whose practice includes palliative patients and their families:

"I believe that the most important endeavour we can undertake as a profession is to become experts at difficult conversations.

If we were better at talking with people at the most troubling time of their lives, the effect on patients, their loved ones, and on health professionals would be both beneficial and far-ranging".

Jennifer Brokaw MD

♥ WHAT RESOURCES ARE AVAILABLE TO UNDERSTAND MY DISEASE MANAGEMENT?

1. Alberta Health Services (AHS):

Advanced Care Planning (ACP) is a way to help you think about, talk about and document your wishes for health care in the event that you become incapable of consenting to or refusing treatment or other care.

- Advance Care planning to be discussed with family and members of your healthcare team.
- Three general approaches to Goals of Care are:
 - Medical Care
 - Resuscitative Care
 - Comfort Care
- Your goals of care are recorded on AHS forms and kept in a **Green Sleeve** (see image below) you keep and take to your healthcare providers. Every time you see a new doctor, take your Green Sleeve with you.

For more information go to:

- www.myhealth.alberta.ca follow links Patients and Family menu to Green Sleeve video
- www.conversationsmatter.ca
- conversationsmatter@albertahealthservices.ca

The most common refrain is, "I'll get to it, eventually". An end-of-life conversation is an ongoing dialogue with your loved ones about values, goals, and beliefs. Get to know your family better today. Share your vision of what living well means to you. Ask loved ones what gives their lives meaning, or what they couldn't imagine living without.



2. Rural Palliative Care Consultation Team (Alberta Health Services Calgary Zone)

- Doctor and Nurse Specialists in hospice palliative care
- When challenges arise for you, such as worsening of your physical condition, or emotional or psychological issues, this team can help
- Please ask your doctor, or nurse, if you'd like a referral to this team
- After Hours: 8 PM to 8 AM. Rural Home Care Nurse: 1-855-955-6665.
 Ask for the after-hours palliative care nurse. That nurse will offer phone advice, access the palliative doctor, if needed, or initiate help from EMS. That nurse will also notify our local Home Care team, who will follow-up with you the next day.



Brochure

3. The Conversation Project:

How to talk to your doctor about your end-of-life care to ensure your wishes for end-of-life care are known and understood by your caregivers.

- www.advancecareplanning.ca/making-your-plan (Speak Up website)
- www.theconversationproject.org



4. Alberta Health Services:

Emergency Medical Services (EMS) Palliative and End of Life Care: Assess, Treat and Refer (ATR) Program. This program is not yet available in the Bow Valley, but we hope it will be, soon. In the meantime, you must go through your local Home Care nurse, or Home Care Response Team, palliative nurse (see Item 2. above, 4th bullet)

For your information, it provides urgent care to people who receive palliative and end-of-life care in their homes. EMS practitioners and your doctor, or nurse, will work together to ensure that the emergency treatment matches your overall care plan.

- www.albertahealthservices.ca/info/Page14899.aspx
- ems.palliative@albertahealthservices.ca

5. Palliative Care Disease Management Resources in the Bow Valley

BOW VALLEY				
Home Care (A.K.A. Community Care)	GPs, RNs, LPNs	Main Office	403-678-7200 Ask for the case manager. Home Care is provided by nurses 8 A.M. to 8 P.M. After hours call 1-855-955-6665 and ask for the after-hours palliative care nurse.	
BANFF				
Mineral Springs Hospital	GPs, RNs, LPNs	304 Lynx Street	403-762-2222 24 hour-a-day nursing care. Emergency Room services.	
Banff Alpine Medical Centre	GPs	201A 211 Bear Street	www.alpinemedical.ca 403-762-3155	
Bear Street Family Physicians	GPs	Suite 302 220 Bear Street	www.mtndocs.ca 403-762-4846	
CANMORE				
Canmore Hospital	GPs, RNs, LPNs	11 Hospital Place	403-678-5536 24 hour-a-day nursing care. Emergency Room services.	
Bow Valley Cancer Centre	GPs & RNs	11 Hospital Place	403-679-7313 Ask for nurse navigator. Open Monday to Friday, 8 AM to 4 PM.	
Bow River Medical Clinic	GPs	202-1205 Bow Valley Trail	www.bowrivermedicalclinic.com 403-609-2136	
Canmore Associate Medical Clinic	GPs	124 - 1151 Sidney Street	www.facebook.com/canmoremedical 403-678-5585	
Ridgeview Medical Centre	GPs	212-1240 Railway Ave	www.ridgeviewclinic.ca 403-609-8333 Offers after-hours care, Monday to Thursday (5 PM to 9 PM), and Saturdays (10 AM to 4 PM) and Sundays (10 AM to 2 PM)	
Three Sisters Obstetrics and Family Medicine	GPs	106-75 Dyrgas Gate	www.threesistersob.com 403-609-9095	
LAKE LOUISE				
Lake Louise Medical Clinic	GPs	200 Hector Road	www.llmc.ca 403-522-2184	

6. Medical Assistance in Dying (MAiD)

Your first discussion about MAiD should be with your doctor, or nurse. We know that end-of-life care and medical assistance in dying are important, sensitive and emotional issues for most people. If you are looking for more information on all end-of-life options please visit:

www.myhealth.alberta.ca/HealthTopics/Palliative-Care

If you are interested in pursuing the process of MAiD, please refer to the graphic for responding to a patient request for Medical Assistance in Dying.

www.AHS.ca/MAID

Follow links Health Professionals and Volunteers Information, and click on:

- Alberta Health Services Policy
- Responding to a Patient Request for Medical Assistance in Dying: Placemat.
- Patient and Families Medical Assistance in Dying Process Map

Write your questions, or notes, here. (You might want to list your doctors, nurses, and current medications and diagnostic tests here.)





2. PHYSICAL CARE AND SUPPORT

2. PHYSICAL CARE AND SUPPORT



WHAT ARE SOME PHYSICAL CHANGES THAT I MAY EXPERIENCE?

When you have received the diagnosis of a terminal illness, your life may dramatically change. Ask your doctor to explain the symptoms you are experiencing. The following is a list of possible symptoms:

- Increasing level of pain
- Nausea and weight loss
- · Changes in level of consciousness and cognition
- Fatigue
- Problems with balance and mobility
- Sensory changes: sight, hearing, smell, touch, taste
- · Physiological: breathing, circulation
- Sexual dysfunction

You may also reach a point where you may need to have further assistance from a trusted caregiver: friend, family member or home care nurse. More information can be found in **Section 3. Social Services and Support**.

WHO ARE THE MOST IMPORTANT PEOPLE I NEED TO TALK TO ABOUT MY PHYSICAL CARE AT THIS STAGE?

- Your doctor: See list of doctor's offices in Section 1. Disease Management, page 13
- Home Care: see list in this section, page 19
- · Family member
- Trusted close friend
- Other

♥ WHAT IMPORTANT INFORMATION SHOULD I EXPLORE?

1. Home Care

Home care offers personal healthcare services for people of all ages. It helps support you in continuing to live in your home and community. Depending on your needs, your care team may include a nurse, doctor, social worker, occupational therapist, physiotherapist or respiratory therapist.

Direct line: 403-678-7200 or 403-943-1920

2. Sorting our Health Concerns

www.virtualhospice.ca Follow the links under Support.

www.myhealth.alberta.ca This is an excellent site with current information directed to Albertans across all aspects of health care. Enter key words in the search box at top right of screen and you will be directed to relevant pages.

3. Caregivers Guide: A Handbook about End-of-Life Care

The caregiver role is integral to end-of-life care. Taking on this role needs careful consideration with expectations clearly outlined. The handbook below is an excellent resource for people in this role.

Hard copies of the Guide eventually will be available at the PCSBV office.



© The Military and Hospitaller
Order of St. Lazarus of Jerusalem

www.hospicetoronto.ca/PDF/Ashcaregiverandbook_CHPCA.pdf

4. What to Expect when you are dying

This document lists what changes you may experience as you approach the last few days or weeks of your life. www.covenantcare.ca/media/6990/20150827-duclina-hospice-what-to-expect-when-a-person-is-dying.pdf

5. Are you at Risk of Falling?

As your disease progresses you may experience weakness and balance issues.

Finding Balance: www.findingbalancealberta.ca

Or, call **Health Link at 811** (24 hours a day, 7 days a week)

6. Fatigue

Most people with cancer, and other terminal illnesses, experience cancer- or disease-related fatigue, but each person's experience is different. Knowing how to manage cancer related fatigue can improve your physical well-being and quality of life.

www.myhealth.alberta.ca/Alberta/Pages/cancer-fatigue.aspx

PDF: How to Manage Cancer-Related Fatigue

Cancer Related Fatigue: Dr. Mike Evans

www.youtube.com/watch?v=YTFPMYGe86s

23 and ½ Hours: Dr. Mike Evans

www.youtube.com/watch?v=aUaInS6HIGo



FALLIATIVE CARE RESOURCES FOR PHYSICAL CARE IN THE BOW VALLEY

RESOURCE	PROFESSION	CONTACT INFORMATION	OTHER
Doctors' Offices	GPs	When you call the doctor's office, ask for a doctor trained in palliative care. Several local doctors have this expertise. A list of doctor's offices in the Bow Valley is shown in Section 1. Disease management, page 9	
Home Care (Banff and Canmore)	RNs, LPNs	Call: 403-678-7200. Also available are home care aides, occupational therapists, respiratory therapists, social workers, dietitians and pharmacists.	Ask for case manager
Bow Valley Community Cancer Care	GPs & RNs	1100 Hospital Place Canmore, AB T1W 1N2 403-678-7200 Main Desk	Ask for Cancer Care Navigator
Rural Palliative Care Consultation Team	Palliative spe- cialist doctors and nurses	Available only by referral through your nurse or doctor	
Local Pharmacies	Pharmacists	Check the yellow pages, or the Internet for a list of local pharmacies in Banff and Canmore	One-to-one medication counselling
Medical Equipment	Canmore	Medic Comforts #1 1302 Bow Valley Trail Canmore, AB T1W 1N6 403-678-3002	
and Supplies	Banff	Gourlay's Banff Pharmacy 220 Bear Street Banff, AB T1L 1B1 403-762-2516	
Alberta Aids to Daily Living (AADL)	Home Care RN refers you to the Provincial Program	780-644-9992 (Edmonton) 1-877-644-9992 (Toll-free) www.alberta.health.ca/services/aids-to- daily-living	Covers 75% cost of catheters, incontinence pads, bath equipment, wheelchairs etc.
Seniors Blue Cross & Palliative Drug Benefits (Two separate programs)	Home Care RN refers you to Provincial Programs	1-800-661-6995 www.bluecross.ca 780-427-1432 Palliative Drug Benefits www.alberta.health.ca/services/drugs-pal- liative-care	Covers most costs of prescriptions for those receiving palliative care. Also covers ambulance.
Canmore General Hospital	GPs, RNs, LPNs, full complement of professional support staff	www.albertahealthservices.ca/info/facility. aspx?id=1000951 1100 Hospital Place Canmore AB T1W 1N2 403-678-5536	2 dedicated palliative care beds
Mineral Springs Hospital	GPs, RNs, LPNs, full complement of professional support staff	www.albertahealthservices.ca/findhealth/ facility.aspx?id=1772 305 Lynx Street Banff AB T1L 1H7 403-762-2222	2 dedicated palliative care beds

WHAT OTHER RESOURCES MAY HELP?

Sexual Health

OASIS stands for Oncology and Sexuality, Intimacy and Survivorship program. This program helps support people with cancer to adjust to sexual changes. It offers clinical services and education for people who have cancer and for healthcare providers.

www.myhealth.alberta.ca/HealthTopics/Cancer-and-sexuality

• Dealing with Hair Loss

Chemotherapy and radiation therapy attack cells in your body that grow rapidly, such as cancer cells. Hair cells are normal cells that also grow quickly and are also affected by the treatment.

www.myhealth.alberta.ca/health/pages/conditions.aspx?hwid=aa151672&#aa151675

The Canadian Cancer Society provides "Wig Rooms" where you can find new and used wigs and other accessories to use while dealing with cancer.

Call **1-888-939-3333** or visit: www.cancer.ca (search for Find a Wig)

Mouth and Dental Care

Good mouth care is very important after cancer treatment.

www.myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=hw144414#hw144416

Write your questions, or notes, here. (You might want to list your doctors, nurses, and current medications and diagnostic tests here.)





3.SOCIAL SERVICES AND SUPPORT

3. SOCIAL SERVICES AND SUPPORT



A social response to support those suffering from a terminal disease is essential to the well-being of a community. It involves cultural values, beliefs and practices. It also focuses on relationships and roles with family, friends and community. Without social support, communities and individuals suffer duress, often in isolation. Providing a safe and comforting environment is the aim of social support.

Please see **Section 4. Spiritual Care and Support**, page 30, for community pastoral support; and, **Section 7. Community Services and Support**, page 47, for a list of many helpful community and social resources.

In this Section we present education resources and community programs to help you navigate through the challenges placed on your relationships.

The following practical information includes advice for:

- · Communicating at the end of life
- · Coping with a terminal illness and promoting emotional health
- Becoming a caregiver

For additional social support, refer to the Introduction, **Meet Your Team**, on page 4. They can provide extra in-person support and refer you to additional supports you may need.

COMMUNICATION AT THE END OF LIFE

We often hear patients and families say "How do I tell my children?", "What do I say when I visit?", "What if I say the wrong thing?". It is often difficult to know what to say.

The following resources offer ideas to make conversations between you, your family and your community a bit easier.

The Canadian Virtual Hospice web site is an excellent source of communication information. You will find:

- Advice for talking with children
- Advice for visiting
- Knowing what to say
- Sending condolences
- Talking with health care professionals

www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Communication.aspx www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/Asked+and+Answered.aspx

WHAT DO I SAY TO MY CHILDREN OR GRANDCHILDREN?

Talking to children about death can be one of the most difficult tasks we do as adults. Many of us need some advice on how best to talk to our children (see also the "Book and Music List" on the PCSBV web site, for many excellent books about death, specifically for children).

Please refer to the following, which includes:

- Suggestions on starting the conversation
- Using open and honest communication
- Using simple and clear language
- Discerning when professional help is needed

www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Communication.aspx

WHO CAN I TALK TO ABOUT CONVERSATIONS WITH MY FAMILY ABOUT HOSPICE PALLIATIVE CARE?

Your doctor may refer you to the Alberta Health Services, Rural Palliative Care Consultation Team. A nurse practitioner, or specialized palliative care doctor will meet with you and your family wherever you are receiving care: your home, hospital, or assisted living facility. They can help you navigate through difficult conversations.

For some additional advice on how to talk to your health care provider, see:

www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Communication/Tips+-for+Talking+with+Your+Health+Care+Providers.aspx

Online Option:

You can also connect with an online Palliative professional through the Canadian Virtual Hospice. This team is made up of doctors, clinical nurse specialists, a social worker, a pharmacist and a spiritual care advisor who specialize in the care of individuals and families living with terminal illness, or loss.

To "Ask a Professional" on the Canadian Virtual Hospice site, see:

www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/Ask+a+Professional.aspx

Many families who have cared for a family member have told us it can be overwhelming and exhausting, and, at the same time, satisfying and life-enriching. To learn more about coping strategies, read the topics related to emotional health in the following link:

www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Emotional+Health.aspx

WHAT OTHER COMMUNITY PROGRAMS AND SERVICES ARE AVAILABLE?

Please go to Section 7. Community Services and Support, page 47, for a list of available programs and services.

WHAT RESOURCES ARE AVAILABLE TO SUPPORT MY SPOUSE AND ADULT CHILDREN, WHO ARE MY PRIMARY CAREGIVERS?

Becoming a primary caregiver may not be naturally comfortable, or realistic, for you, or other family members. If you are unsure about whether, or not, you want to provide personal care in your home, we encourage you to discuss this with your Home Care nurse, or family doctor.

If you are interested in becoming, or continuing to be, a caregiver, we suggest you, again, visit the Canadian Virtual Hospice web site, under "Providing Care".

Topics include:

- Understanding death and dying
- Sleep and caregivers
- Caring for grieving children and youth
- Caring for yourself
- Providing Care
 - Help with medication, eating, bathing, toileting
 - Care of the mouth
 - Caring for face and hair
 - Preventing pressure sores

www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Providing+Care.aspx



WHAT OTHER RESOURCES ARE AVAILABLE FOR CAREGIVERS?

The Champlain Hospice and Palliative Care Program, in Ottawa, offers excellent practical strategies for support and self-care for caregivers.

www.champlainpalliative.ca/for-caregivers-patients/support-for-caregivers/

And, The Order of St. Lazarus online caregiver training www.stlazarus.sjatraining.ca/registercertprog.php



Write your questions, or notes, here.					
	_				
	_				
	_				
	_				
	_				
	_				
	_				





4. SPIRITUAL CARE AND SUPPORT

4. SPIRITUAL CARE AND SUPPORT



WHAT DOES SPIRITUALITY MEAN?

When everything is considered, it is the relationships we have with self, others, the natural world, the future, the past, and the ultimate reality, or God, that give rise to spirituality.

Research has shown that people with terminal illnesses:

- Consider their quality of life improved when their spiritual needs have been met
- · Value and frequently use spiritual beliefs and practices as a way to help cope with their situation
- Often want to talk about spiritual issues

Spirituality involves trying to find meaning and purpose in what is happening to us. It is fundamental to each person's journey through life, a journey that yields a sense of who we are. A question you may ask yourself: Do I have a faith I can depend on?

Spiritual suffering, often called total suffering, goes beyond physical pain and may include emotional and psychological suffering. It may involve intense grief and deep sadness. There may be a loss of dreams, future and living life without loved ones.

The illustration below shows transformation, or movement, across the spectrum of spiritual well-being.

Total Spiritual Pain Spiritual Struggles Total Spiritual Well-being Emotional withdrawal Meaninglessness Isolation or Abandonment Connectedness Meaning Guilt Sadness Suffering Hope and Trust Life after Death

Spectrum of Spiritual Pain and Spiritual Well-being

WHAT WILL I FIND IN THIS SECTION?

In this Section you will find resources relating to spiritual care, which usually involves support in difficult situations, such as loss, and matters of life and death. Resources include people to talk to, taken from the local Bow Valley Community Church list, and reading material including books and pamphlets. Related material can be found in **Section 3. Social Services and Support**, page 23, and **Section 5. End-of-Life Care**, page 35, of this guide. Electronic links can be found under this Section in The Book of Links, page 65, especially the link to the Canadian Virtual Hospice.

WHAT ARE THE MOST IMPORTANT RESOURCES FOR ME TO KNOW ABOUT?

1. Spiritual Resources and Community Church List

DENOMINATION	NAME	ON CALL	PHONE	LOCATION
Anglican	St. Michael's	Rev. Howard Thornton	403-707-7140	Canmore 709 7 Street
Anglican	St. George In The Pines	Rev. Howard Thornton	403-707-7140	Banff 101 Beaver Street
Baptist Doctrine	Banff Park Church	Pastor John Park	403-497-5125	Banff 455 Cougar Street
Baptist	Mountain Baptist	Rev. Trevor Sato	403-609-3312	Canmore 709 7 Street
Catholic	Our Lady of the Rockies	Fr. Wilbert Chin Jon	403-675-5044	Canmore Under Construction
Catholic	St. Mary's Parish	Fr. Dan Stevenot	403-762-3450	Banff 1B1, 305 Squirrel Street
Gospel	Full Gospel Church	Pastor Kevin Driver	403-497-4703	Banff 407 Cougar Street
Gospel	Trinity Bible Church	Pastor Tim McAlpine	403-678-5063 403-483-6960	Canmore 1717 Bow Valley Trail
Jehovah's Witness	Jehovah's Witness Kingdom Hall	Ron Carbert	403-688-1304	Canmore 122 15 Street
Lutheran	Shepherd of the Valley	Pastor Mark Lobitz	403-637-2650	Canmore 1205 1 Avenue
Presbyterian	St. Paul's	Rev. Clay Kuhn	403-609-0872	Banff 298 Banff Avenue
Seventh Day Adventist	Mountain Sanctuary	Pastor Lester Carney Doctor Check San	403-678-0928 403-560-6868	Canmore 1205 1 Avenue
United	Ralph Connor Me- morial	Rev. Greg Wooley	403-493-4923	Canmore 617 Main Street
United	Rundle United	Rev. Murray Speer	403-762-2075 403-762-3588	Banff 302 Buffalo Street
Non-Denominational	Cross Way Com- munity Church	Pastor Daniel Bittle	403-678-9801	Canmore 2-117 Bow Meadows Crescent

2. Alberta Health Services (AHS) Palliative and Spiritual Care Volunteers

Palliative volunteers in the Bow Valley are available through Volunteer Services located at the Canmore Hospital. They provide compassionate companionship in many different ways and may be found in the Banff and Canmore hospitals, lodges, your homes or long-term care facilities. For more information, call: 403-678-7253.

Covenant Health at the Banff Mineral Springs Hospital also provides volunteers who are committed to improving the quality of the patient and family experience. For more information, call: 403-760-7222.



3. Mindfulness Meditation

Since 2009, the Canmore and Area Health Care Foundation (CAHCF) has funded Mindfulness Programs every Spring and Fall. The programs introduce you to meditation and yoga, to help you manage everyday stressors and improve your overall health. Benefits may include improved sleep, decreased stress, enhanced ability to cope with pain, reduction in the use of medication, an improved immune system and less anxiety.

"This is by far one of the most popular programs offered at the Canmore Hospital." The programs are open to anyone in the community, including healthcare staff.

Contact: Deanna Thompson or Suzanne Lawrence

Phone: 403-678-7208.

Email: mindfulnessmeditation2012@gmail.com

www.canmorehealthfoundation.com/mindfulness-program-meditation-and-yoga-for-stress/

4. The Role of Natural Places in Rural Palliative Care

Parks and nature are known to influence quality of life at all phases, including end of life and for those experiencing grief. Parks and nature reveal life and death, and nature teaches people to grieve. Alberta Parks and Mt. Royal University are working together to promote access and enjoyment of parks and nature for people nearing end of life, and for grieving family members.

Contact: Sonya Jakubec, Mt. Royal University

Phone: 403-403-440-5075

ARE THERE OTHER RESOURCES I MAY WANT TO CONSIDER?

1. Alpine Voices Threshold Choir

"Kindness Made Audible": This is the motto of the Threshold Choir. The voice is a true and gracious vehicle for compassion and comfort. The Threshold Choir honours the ancient tradition of singing "a capella" at the bedside of those who are sick or dying, or in need of nurturing song. Only 3-4 members sing at the bedside at any given time.

Contact: Choir Director, Jan Tissandier

Call: 403-678-2233

Inreshold Cheir

2. Death Café

At a Death Café, people, often strangers, gather to eat cake, drink tea and discuss death. Its objective is to increase awareness of death with a view to helping people make the most of their (finite) lives.

A Death Cafe is a group-directed discussion of death with no agenda, objectives or themes. It is a discussion group rather than a grief support or counselling session.

Contact: Genevieve Wright

Call: 403-609-1230

www.facebook.com/deathcafecanmore

3. Healing Pathways

Healing Pathways is a practice of gentle touch that supports the healing of body, mind, and spirit. Rooted in the ancient Christian tradition of laying on of hands, this service is offered free to anyone seeking the Spirit's healing grace, at whatever stage of life or health. A session of Healing Pathway is a gift to one's self – nurturing and restorative.

Contact: Sue Nichols. P: 403-678-4536 or Vicky Connoy. P: 403-609-0428

4. McInnis and Holloway Library

Often, when you are grieving you wonder where to turn for support. Grieving can take months, even years, to work through. McInnis and Holloway has developed a grief support and educational service for the community. Olive Branch Support Services includes:

- Family Follow-up
- Support and Referral Service
- Education Services for Groups

See the web site in THE BOOK OF LINKS or call: 403-276-2296

Write your questions, or notes, here.





5. END-OF-LIFE AND DEATH MANAGEMENT

5. END-OF-LIFE CARE AND DEATH MANAGEMENT



While living with a terminal illness, there may be moments when you don't know where to start, or who to ask, as you prepare for the end of life. Following is a "road map", to help you start, or continue, along your journey, organized into "steps", to show some of the priorities.

HOW DO I START TO PREPARE FOR THE END OF LIFE?

Step 1: Create a Personal Directive

A Personal Directive names someone (an "Agent"), whom you've chosen to make decisions regarding health matters. The agent steps in when you are unable to make your own decisions because of illness, or injury. This could be temporary or long term.

- This is a legal document, but does not need to be authorized by a lawyer. You can, however, ask your lawyer to authorize your Personal Directive.
- How do I complete a Personal Directive?
 - Read Instruction Sheet for Personal Directive Form www.alberta.ca/assets/documents/opgt-form-personal-directives-form-opg5521a.pdf
 - Complete the Personal Directive Form: see the following link www.ddsf.ca/ESW/Files/Personal_Directive_Form.pdf
 - Ensure your Agent agrees to this role
 - A social worker can help you with this
 - Give a copy to your Doctor, your agent(s), and any organization that is responsible for your care (e.g. Assisted Living)

Step 2: Discuss your Goals of Care with your Doctor

"Goals of Care" (GOC) is a medical order, a 2-page form, used to describe and communicate the general aim, or focus, of care including the preferred location of that care. Your GOC designation:

- Ensures your voice is heard when you can no longer speak for yourself
- The GOC form is kept in a "Green Sleeve", a transparent plastic sleeve, prepared by Alberta Health Services (AHS) and containing several other Advance Care Planning resources
- Should be placed on, or near, your fridge in the event EMS responds to an emergency in your house
- Should be taken to your doctors' appointments, including your GP and any specialists you see

For educational videos on GOC, see www.myhealth.alberta.ca

Step 3: Create an Enduring Power of Attorney

In Alberta, you need to create an "Enduring Power of Attorney" (EPA) to give a person you've chosen the legal authority to act on your behalf with respect to your financial affairs while you are alive.

An EPA:

- Can take effect immediately, or if you lose mental capacity
- Does not give someone the legal authority to make decisions about your health care. A Personal Directive is required for this.

To read a booklet about what is involved in making an Enduring Power of Attorney, please see www.cplea.ca/wp-content/uploads/MakingAnEnduringPowerOfAttorney.pdf

Step 4: Complete your Will

A Will is a legal document that allows you to decide how your finances, estate, and property are distributed after death. A Will can also name a guardian for any minors after your death.

- · We recommend you consult a lawyer to prepare your Will
- If you die without a Will, your estate will face legal and administration fees to determine how the estate is distributed
- It is important to talk to your Enduring Power of Attorney, to ensure they:
 - Agree to this role
 - Have a paper copy of your Personal Directive, Enduring Power of Attorney and Will, and knows the location of these documents
- For more information, please see www.alberta.ca/wills-in-alberta.aspx

Step 5: Complete Your Advance Care Plan (ACP)

Advanced Care Planning Is a way to help you think about, talk about and document wishes for health care if you become incapable of consenting to, or refusing, treatment, or other care. (see **Section 1. Disease Management**, page 9, for more information).

For more information, see Advanced Care Planning and Conversations Matter

Step 6: Create a Legacy

In palliative care, we refer to legacy activities as an intentional way for families and friends to create special moments together before death occurs.

- A hospice in Waterloo suggests some of the following activities to help families and friends create memorable moments together:
 - Create a scrapbook with pictures/keepsakes related to a particular time in your life
 - Create a photo album of favourite photos with accompanying captions
 - Compile a binder of favourite recipes
 - Compile a collection of favourite songs or hymns
 - Create a quilt made out of your favorite T-shirts or other fabric items
 - Handprints of you and/or your loved ones in plaster
 - Write cards, or purchase gifts, for a future birthday, holiday or special occasion
 - Write a poem or a song created specifically for your loved one(s)
 - Plant a tree
 - Ethical Wills: write a letter to your family that shares your personal & family values, beliefs, spiritual values, accomplishments, hopes/wishes, life lessons, forgiveness etc.

www.hospicewaterloo.ca/resources/legacy-activities

- On a flat bed sheet trace the body of a child or grandchild. This sheet can represent a hug when you cover your loved one.
- The Canadian Broadcasting Corporation (CBC) featured the following article on Legacy work. It is entitled "A Dying Patient Leaves a Legacy". Please consider reading this article:

www.cbc.ca/news/health/a-dying-patient-leaves-a-legacy-1.1044966

Step 7: Prepare for the Final Days

As death approaches, sometimes individuals and families find comfort in preparing for these final days. This can help you and your family to know what to expect. To prepare for these final days, we invite you to visit the Canadian Virtual Hospice web site to learn more about:



- How to prepare when death is near
- What may happen after death
- How to care for the body after death
 www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Final+Days.aspx

Step 8: Dying at Home: EDITH Protocol

The "Expected Death in the Home" (EDITH) is an Alberta Health Services protocol and supports end-of-life care in the home. It documents an individual's express wishes to plan for pronouncement, or certification, of death in the home. Please ask your Home Care nurse for more information.

Step 9: Planning Your Funeral

You can either pre-plan your funeral, or ask others to plan your funeral, before, or after death.

- If you or your family require guidance with planning your funeral, please see the following booklet: "Saying Farewell: A Guide to Assist You with Preplanning and With the Death and Dying Process". www.seniors-housing.alberta.ca/documents/Saying-Farewell-Dying-Process-Guide.pdf
- Locally, Bow River Funeral Service can help you plan your funeral.
 Call Russ and Wendy Reynolds at 403-678-4880, Canmore, or 403-762-2159, Banff.
 www.bowriverfuneral.com/index.php?f=about
- For advice on internment in the Canmore cemetery, the Town of Canmore can offer advice at 403-678-1599 (Lorna Kuhn, Parks Cemetery Coordinator) www.canmore.ca/municipal-services/cemetery-services
 In Banff call 403-762-1240 (Operations Department) www.banff.ca/index.aspx?NID=432

WHERE CAN I ACCESS INFORMATION ABOUT MEDICAL ASSISTANCE IN DYING (MAID)?

In February 2015, the Supreme Court of Canada passed legislation to allow eligible Canadians adults to request medical assistance in dying. For more information on MAiD, please see the following two web sites, and speak directly to your doctor and health care team.

Government of Canada: Medical Assistance in Dving

www.canada.ca/en/health-canada/services/medical-assistance-dying.html

Alberta Health Services

www. albertaheal thservices. ca/assets/info/pf/if-pf-maid-faqs-public.pdf

See also **Section 1. Disease Management**, page 9.

Write your questions, or notes, here.	

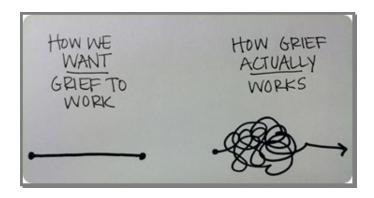




6. LOSS AND GRIEF



WHAT IS THIS SECTION ABOUT?



"Things that matter can be expressed in simple ways." Peter Petrik

Loss and grief: We know what this is about. Grieving is a most personal process each of us will have to deal with at a time of great loss. Most of us have suffered grief in our lives, shed tears, endured deep sadness. Cultural norms and customs may be helpful but, in the end, we have to face the loss of a dear one in our own way. In hospice palliative care, loss and grief commonly begins when a diagnosis of terminal illness is given, and fluctuates and changes as you live the rest of your life.

Look, again, at the model of hospice palliative care in the **Introduction**, page 3. Loss and grief follows along that same pathway and continues long after a loved one has died.

WHAT RESOURCES ARE AVAILABLE THAT WILL HELP ME RIGHT NOW?

We hope that the following resources will provide encouragement and support as you make your way through this difficult process. Resources and supports include people to talk to, pamphlets and papers to read, and web sites to visit, including the Palliative Care Society of the Bow Valley **www.palliativecarebowvalley.com**.

♥ WHO CAN I TALK TO ABOUT WHAT I'M GOING THROUGH?



There are many professional counsellors available in our Bow Valley communities who provide grief counselling as part of the every-day practice. In addition, there are community supports available, which provide group, or other support. The following table shows you who they are.

\$\times\$ LOSS AND GRIEF: PEOPLE TO TALK TO

NAME, OR ORGANIZATION	CONTACT INFORMATION	COMMENTS				
Right Now: Local Individual & Family	Right Now: Local Individual & Family Counselling Services					
Local Pastors & Clergy	See list of spiritual resources on page 30 in Section 4. Spiritual Care	No charge. Personal & cultural choice for spiritual support.				
Canmore Mental Health Services	101, 743 Railway Avenue, Canmore Call: 403-678-4696 24 hour Help Line 1-866-332-2322 Self-referral call: 1-877-652-4700	No charge. Professional social workers & psychologists. Special grief support for youth.				
Banff Mental Health Services	303 Lynx Street, Banff Call: 403-762-4451	No charge. Professional social workers & psychologists.				
Town of Canmore FCSS	902 7 Avenue, Canmore, AB Call: 403-609-3743 Call: 403-678-7131	No charge. Coping with Loss and Grief work- shops. Runs twice a year. Also, one-on-one counselling.				
Town of Banff FCSS	110 Bear Street, Banff AB Call: 403-762-1251	No charge. Grief Recovery Program. 8-week group sessions or 7-week individual sessions. Fee \$250.				
Janet McLeod, Psychologist	Call: 403-609-0675 Banff and Canmore	General + Grief Counselling. Approx. cost: \$150+ per hour				
Renee Jean Meggs, Psychologist	Call: 403-609-3044 Banff and Canmore	General + Grief Counselling Approx. cost: \$150+ per hour				
Tannis Brayer, Psychologist	Call: 855-743-8230 Banff and Canmore	General + Grief Counselling Approx. cost: \$150+ per hour				
Barb Dobson, Psychologist	Call: 403-688-1033 Canmore	General + Grief Counselling Approx. cost: \$150+ per hour				
Melissa & Michael Judcovitch Canmore Counselling	Call: 403-609-9107	General + Grief Counselling Approx. cost: \$150+ per hour				
Margaret Claveau Certified Counsellor	Call: 403-609-4992 Canmore	Grief & Grief Counselling Approx. cost: \$150+ per hour				
Maybe Later: Regional Support Servi	ices					
Alberta Health Services Bob Glasgow Grief Support Centre	1820 Richmond Road SW, Calgary Call: 403-9558011	No charge. Individual counselling up to 8 weeks. Group support groups for 6 weeks.				
Banff, Canmore, Big Horn Regions	Mountain Sanctuary	Connects you to community, social and government resources.				
Walking With Grief Together (in Fish Creek Park)	Sonya Jakubec P: 403-440-5075 sjakubec@mtroyal.ca	Provided by Alberta Parks, Mount Royal University and Friends of Fish Creek Park.				
Compassionate Friends	Call: 403-256-3820 Calgary@TCFCanada.net	A monthly support group for parents (and their surviving children) after the death of their child.				
Hospice Calgary Sage Centre	1245 70 Avenue SE, Calgary Call: 403-263-4525	Child, teen & family counselling and grief services.				
McInnis and Holloway	Call: 403-243-8200	Grief library. A wealth of articles and videos on grief.				
Soul Passages	sarah@soulpassages.ca Calgary, AB	Sarah Kerr, PhD. Helps people navigate death, loss and transformation.				



NAME, OR ORGANIZATION	CONTACT INFORMATION	COMMENTS
Tom Baker Cancer Centre	1331 29 Street NW, Calgary Call: 403-355-3207	No charge. No referral req'd. Individual and group support.
Wellspring, Calgary (Focus is Cancer)	1404 Home Road NW, Calgary Call: 403-521-5292	Thursdays with Bob: Reflections on grief and loss. Chaplain in residence. Bereavement support.

WHAT OTHER TYPES OF RESOURCES ARE AVAILABLE THAT COULD HELP ME THROUGH THIS?

1. Internet:

Canadian Virtual Hospice. One of the best Internet sources of information.

Go to **www.virtualhospice.ca**, then under Topics pick Emotional Health, then pick Grief Work.

Canadian Virtual Hospice. Another excellent source of information on grief. www.mygrief.ca Children's Grief - www.kidsgrief.ca

2. Social Media:

SLAP'D is the social media for teens who have lost a parent to find hope and connection through shared experiences.

3. CBC Radio:

Children are the "hidden mourners" in our society, says child health expert. The Sunday Edition with Michael Enright. Sunday, February 4, 2018.

4. Information Handout:

When Grief Goes to School, Five Tips for Parents. Published by Hospice Calgary.

5. Booklet by Kathy Cloutier:

Customs and Traditions in Times of Death and Bereavement. Available through McInnis and Holloway (see The Book of Links, page 65)

6. MAiD and Grief (talk to someone):

Call Calgary Chapter Dying with Dignity. 403-730-2480.

9. Books: (see also Books and Music List at the end of this Guide)

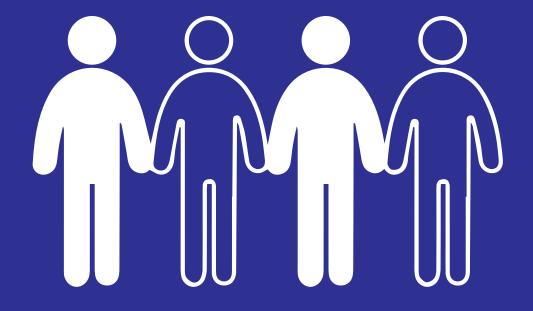
- a. A Grief Observed: C. S. Lewis
- b. Being Mortal, Medicine and What Matters in the End: Atul Gawande
- c. Final Gifts: Maggie Callanan & Patricia Kelley
- d. Healing Your Grieving Heart for Teens: 100 Practical Ideas: Alan Wolfelt
- e. Kitchen Table Wisdom: Rachel Naomi Renen
- f. On Grief and Grieving: Finding the Meaning Grief Through the 5 Stages of Loss: Elizabeth Kübler-Ross
- g. **Our Shared Journey:** A Guide to Manage Stress and Sleep; Guide on Grieving and Healing; Guide to Our Relationships: *Canadian Hospice Palliative Care Association*
- h. Talking About Death Won't Kill You: Dr. Kathy Kortes-Miller
- i. **Tear Soup (good for kids):** Pat Schwiebert, Chuck DeKlyen
- j. Tuesdays with Morrie: Mitch Albom

Please Don't Ask Me If I'm Over It Yet

by Rita Moran

PLEASE, don't ask me if I'm over it yet. I'll never be over it. PLEASE, don't tell me she's in a better place. She isn't with me. PLEASE, don't say at least she isn't suffering. I haven't come to terms with why she had to suffer at all. PLEASE, don't tell me you know how I feel Unless you have lost a child.	PLEASE, don't tell me at least you had her for so many years. What year would you choose for your child to die? PLEASE, don't tell me God never gives us more than we can bear. PLEASE, just tell me you are sorry. PLEASE, just say you remember my child, if you do. PLEASE, just let me talk about my child. PLEASE, mention my child's name.	
PLEASE, don't ask me if I feel better. Bereavement isn't a condition that clears up.	PLEASE, just let me cry.	
Write your questions, or notes, here.		





7. COMMUNITY SERVICES AND SUPPORT

7. COMMUNITY SERVICES AND SUPPORT



Living with a terminal illness can often cause patients and families to feel isolated and distant from their communities. But, communities often do astonishing things to support their friends, neighbours and the community as a whole. The table below identifies some community resources in the Bow Valley and the Calgary area that may benefit you and your family. **The Book of Links,** on page 65, provides additional electronic information for you.

This Section has information similar to that found in **Section 3. Social Services and Support** on page 23, **Section 4. Spiritual Care and Support** on page 29, **Section 6. Loss and Grief** on page 41. Please check them out for more information.

**AHS = Alberta Health Services. FCSS = Family & Community Support Services. LPN = Licensed Practical Nurse

SERVICES & SUPPORT	ORGANIZATION	CONTACT	COMMENTS
Local: Banff and Canmor	e		
Nursing Care (additional)	AHS: Rural Palliative Care In-Home Funding Program	Call your Home Care nurse, 403-678-7200, or GP, for more information. Funding is approved by Alberta Health Services Care Manager	Additional funding to help pal- liative patients stay at home .
Therapeutic Foot Care	Cheryl Graham LPN Brenda Bonnet	403-679-1529 footcarebycheryl@gmail.com 403-688-6883 above-andbeyond@hotmail.com	Professional foot and toenail care
Medical Supplies and Equipment	Local: Medic Comforts Online	 P: 403-678-3002 #1, 1302 Bow Valley Trail, Canmore www.canmeddirect.ca P: 1-855-422-6633 E: info@canmeddirect.ca 	Valentina has operated this local store for decades
AHS Volunteers provide supportive palliative care	Canmore Hospital Banff Mineral Springs	P: 403-403-678-7253P: 403-760-7222	Ask your nurse, or doctor, for a palliative volunteer
Transportation	TransParent Concierge FCSS Canmore FCSS Banff	 P: 403-707-8184 Don Peterson www.transparentconcierge.com P: 403-678-7130 P: 403-762-1253 	FCSS provides volunteer driver services
Sustainable travel option by car	Poparide	www.poparide.com	Easiest way to share rides between cities
Affordable Community Services	FCSS Canmore	 P: 403-678-7130 canmore.ca/residents/family-com- munity-services/emotional-support P: 403-762-1253 	Financial help for a host of services. Offers grief workshops etc.
	FCSS Banff	www.banff.ca/index.aspx?NID=332	
Respite Care	Canmore Hospital Banff Mineral Springs Home Care	P: 403-403-678-7253P: 403-760-7222P: 403-678-7200	Talk to your nurse, or doctor, about your need for this

SERVICES & SUPPORT	ORGANIZATION	CONTACT	COMMENTS			
Local: Banff and Canmor	Local: Banff and Canmore - continued					
"Life After Caregiving"	Nancy Jackson	P: 403-678-1252 E: nanjac@shaw.ca	Caregiver's support group			
Weekend retreats for Cancer Survivors	Knight's Cabin	www.knightscabin.com	Lisa Belanger			
Seniors 55 years+	Canmore Seniors Association Banff Seniors Association	 P: 403-609-3743 www.canmoreseniors.org P: 403-762-4830 www.banff.ca/index.aspx?NID=220 	Offers wide variety of support e.g. Volunteer Driver Program, Meals on Wheels, Education			
Mindfulness Meditation Program	Canmore & Area Health Care Foundation (CAHCF)	Canmore Hospital P: 403-678-7208 Deanna Thompson or Suzanne Lawrence	Supported by AHS, CAHC Offered twice a year			
Mindful Art Sessions	artsPlace	P: 403-609-2623 950 8th Ave. Canmore www.artsplacecanmore.com	Relief from stress and anxiety			
Conversations About Death	Death Café	P: 403-609-1230 E: lotus.hands@shaw.ca Facebook: deathcafecanmore	All welcome to talk about death over tea & cake			
Yoga (including hot yoga)	The Yoga Lounge	Henri Ferguson P: 403-678-6687 info@theyogalounge.ca	Yoga for cancer survivors			
Errands and Caregiving	A Gift of Time Errands	Brenda Goeres P: 403-609-2575 E: giftoftime@shaw.ca	Errands and caregiving			
Regional: Calgary						
"Sources of Help" Booklet	Tom Baker Cancer Centre	www.albertahealthservices.ca/as- sets/healthinfo/cc/hi-dis-cc-sourc- es-of-help-tbcc.pdf	General information			
Support for Cancer Patients	Wellspring Calgary	P: 403-521-5292 www.wellspringcalgary.ca	Education, Arts, Meditation, Self-Care			
Nature Walks for palliative patients & Walking w/Grief	Alberta Parks and Mount Royal University	P: 403-440-5075 (Sonya Jakubec) E: sjakubec@mtroyal.ca	"Everyone belongs outside."			
Psychologists + Psychia- trists + Social Workers	Tom Baker Cancer Centre	403-355-3207 (no referral req'd) 403-944-4488 (hospice + pall. info)	Psychosocial Oncology. Grief Counselling			
Family Caregiver Centre	Bridgeland Seniors Health Centre	403-955-1674 1070 McDougall Road NE, Calgary	Social Workers			



SERVICES & SUPPORT	ORGANIZATION	CONTACT	COMMENTS
Provincial and National			
Additional Services and Support	AHS Health Link Comm. & Soc. Services	 P: 811 www.myhealth.alberta.ca/811 403-955-8011 P: 211 www.ab.211.ca 	24 hours a day, 7 days a week
Online support groups for those affected by cancer	Cancer Chat Canada	www.cancerchat.desouzainstitute.com	
Support for people caring for a loved one	Alberta Caregivers Association	www.albertacaregivers.org. www.caregiversalberta.ca	Information, education, support and advocacy
Education, Advocacy, Resources	Alberta Hospice Palliative Care Assoc.	1245 70 Avenue SE, Calgary P: 403-206-9938 www.ahpca.ca	
Cancer research, care and prevention	Alberta Cancer Foundation	300, 1620 29 Street NW, Calgary P: 1-866-412-4222 www.albertacancer.ca	
End-of-Life Costs	Canadian Cancer Society	1-800-661-2262 www.cancer.ca/en/?region=ab	Compassionate financial assistance



Write your questions, or notes, here.





8. ADMINISTRATION OF DYING

8. ADMINISTRATION OF DYING



As you may have already experienced, living with a terminal illness can place extra challenges on your family and your finances. The following information will ease some of these challenges by providing you information on the following:

- · Financial assistance at the end of life
- Non-financial assistance for family members and caregivers
- Decision making assistance related to financial and health related matters
- Planning a funeral

WHAT FINANCIAL ASSISTANCE IS AVAILABLE TO ME AND MY LOVED ONES BEFORE I DIE?

1. Financial Assistance for Prescription Drugs, Diabetes Supplies and Ambulance Services

All Alberta residents who have a palliative diagnosis and reside at home, hospice, or a non-publicly funded residence can receive subsidized benefits under the Palliative Blue Cross program. This program subsidizes prescription drugs, diabetes supplies and ambulance services. Ask your doctor or nurse practitioner to apply for this program.

www.health.alberta.ca/services/drugs-palliative-care.htm

2. Financial Assistance for Additional Care in Your Home

(see more information in **Section 1. Disease Management**, page 9 and **Section 2. Physical Care & Support**, page 17)

As of 2017, Alberta Health Services has made available additional funding, to provide extra care in your home, particularly if you want to stay at home longer. Funding can cover costs of part-time or full-time registered nurses, licensed practical nurses, nursing aides, caregivers, and other support services.

For more information, please contact your Alberta Health Services Homecare nurse.

3. Financial Assistance for Family Caregivers: Compassionate Employment Insurance Benefits

Compassionate Employment Insurance (EI) Care benefits are paid to family members who provide support and caregiving to a family member who is at significant risk of death. EI benefits extend up to a maximum of 26 weeks. If you require assistance to apply for EI benefits, ask your social worker for help.

www.canada.ca/en/services/benefits/ei/ei-compassionate.html

4. Life Benefits

Life insurance will often provide for what is known as a living benefit. This benefit allows for people who have been diagnosed with a terminal illness to have a portion of their anticipated benefit paid to them in the years before their death. Taking such benefits will reduce the amount of the insurance benefit ultimately paid to the beneficiary of the insurance. A financial advisor can help you make these kinds of decisions.

5. Tax Credits

People who have costs associated with health-related goods and services, or additional living costs, due to disability, may be eligible for tax credits. To find out more about tax credits that may be available to you, consult with a financial advisor.

6. Alberta Seniors Benefit Program

If you are 65 years of age, or older, the Alberta Seniors Benefit program is an income-based program that provides a monthly income supplement to lower income seniors.

www.seniors-housing.alberta.ca/seniors/seniors-benefit-program.html

7. Special Needs Assistance for Seniors (SNA) Program

If you are 65 years of age, or older, the Special Needs Assistance for Seniors program is an income-based program that provides a lump-sum cash payment to lower-income seniors facing financial difficulties.

www.seniors-housing.alberta.ca/seniors/SNA-submit-claim.html

8. Dental and Optical Assistance for Seniors

If you are 65 years of age, or older, this program provides financial assistance for basic dental and optical services. www.seniors-housing.alberta.ca/seniors/dental-optical-assistance.html

9. Property Tax Deferral

If you are 65 years of age, or older, the Seniors Property Tax Deferral Program (SPTDP) allows eligible senior homeowners to defer all or part of their property taxes through a low-interest home equity loan with the Alberta government.

www.seniors-housing.alberta.ca/seniors/property-tax-deferral.html

10. Assured Income for the Severely Handicapped

Assured Income for the Severely Handicapped (AISH) provides financial and health benefits for adult Albertans who have a permanent disability that severely impairs their ability to earn a living. The level of benefits depends on income and assets.

www.alberta.ca/aish.aspx

11. Alberta Aids to Daily Living (AADL)

The Alberta ADL program helps Albertans with a long-term disability, chronic illness or terminal illness to maintain their independence at home, in lodges or group homes by providing financial assistance to buy medical equipment and supplies.

www.health.alberta.ca/services/aids-to-daily-living.html

12. Disability Tax Credit

The Disability Tax Credit is a non-refundable tax credit that helps persons with disabilities, or their supporting persons, reduce the amount of income tax they may have to pay. Note: Nurse practitioners can certify the applicants, especially in rural areas.

www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html?utm_campaign=not-applicable&utm_medium=vanity-url&utm_source=canada-ca_disability-tax-credit

13. Income Support

Income Support from Alberta Human Resources & Employment provides financial benefits to individuals and families who do not have the resources to meet their basic needs, like food, clothing and shelter.

www.alberta.ca/income-support.aspx



14. Canada Pension Plan Disability Credit

The Canada Pension Plan Disability Credit provides benefits to people have made enough contributions to the CPP, and who are disabled and cannot work at any job on a regular basis. Benefits may also be available to their dependent children.

www.canada.ca/en/employment-social-development/programs/pensions/reports/disability-benefits. html#h2.2

15. Canada Pension Plan (CPP) Survivor Benefits

When a contributor dies, CPP survivor benefits are paid to the contributor's estate, surviving spouse or common-law partner, and dependent children. To receive CPP benefits, you must apply for them. There are three types of benefits:

- Death benefits: a one-time payment to the estate of a deceased CPP contributor
- Survivor's pension: a monthly pension paid to the surviving spouse or common-law partner of a deceased contributor
- Children's benefit: a monthly benefit for dependent children of a deceased contributor. Dependent children are those under 18, or between the ages of 18 and 25 and attending school or university full-time

16. Canada Revenue Agency (CRA)

The CRA gives instructions on "What to do when someone has died".

www.canada.ca/en/revenue-agency/services/tax/individuals/life-events/what-when-someone-died.html Please consult your accountant for further advice.

WHAT NON-FINANCIAL ASSISTANCE IS AVAILABLE TO MY FAMILY, OR CAREGIVERS. BEFORE I DIE?

17. Compassionate Care Leave for Caregivers

Under the Alberta Government legislation, eligible employees may take up to 27 weeks off of work (unpaid) to care for family member with a terminal illness, without risk of losing their job. To be eligible, employees must be employed for over 90 days with the same employer.

www.alberta.ca/compassionate-care-leave.aspx

WHAT IF I AM UNABLE TO MAKE DECISIONS ABOUT MY HEALTH CARE?

18. Create a Personal Directive

In Alberta, you will create a Personal Directive to identify someone (referred to as an "agent"), to act on your behalf when you are unable to make your own decisions. Your agent will have legal authority to make personal decisions that are non-financial, such as medical treatments and your place of residence.

www.ddsf.ca/ESW/Files/Personal Directive Form.pdf.

HOW DO I CREATE A PERSONAL DIRECTIVE?

- Print and complete the form in this link, as soon as possible www.ddsf.ca/ESW/Files/Personal Directive Form.pdf
- Read instruction sheet for Personal Directive Form
 www.alberta.ca/assets/documents/opgt-form-personal-directives-form-opg5521a.pdf
- Ensure your agent agrees to this role
- Give a copy to your doctor, your agent(s), and any organization that is responsible for your care (e.g. Assisted Living Facility)
- NOTE: This is a legal document, but does not need to be authorized by a lawyer. However, you can ask your lawyer to authorize it.

19. Create an Enduring Power of Attorney (EPA)

In Alberta, while you are alive, you need to create an EPA, and choose a person with the legal authority to act on your behalf with respect to your financial affairs. This can take effect immediately, or when you lose mental capacity. It does not give someone the legal authority to make decisions about your health. (see number 18, above, about a Personal Directive.)

HOW DO I CREATE AN EPA?

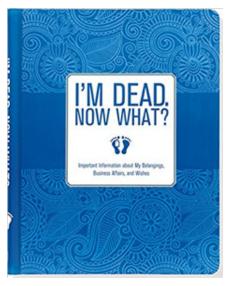
Start by reading the following booklet about what is involved in making an EPA:
 www.cplea.ca/wp-content/uploads/MakingAnEnduringPowerOfAttorney.pdf

20. "I'm Dead, Now What?"

This book helps you organize and communicate important information to your Enduring Power of Attorney and your agent for your Personal Directive, about health, legal and personal matters.

You can purchase this book for under \$20.00 at

- Cafe Books in Canmore
- Amazon.ca
- Bow River Funeral Service



© Peter Pauper Press



SOUR CAN YOU PROVIDE ME WITH INFORMATION ABOUT PLANNING MY FUNERAL? I DON'T KNOW WHERE TO START.

The Alberta Government created a helpful booklet titled "Saying Farewell: A Guide to Assist You with Preplanning and with the Death and Dying Process". Please consider downloading and printing this document to help you, or your family, plan your funeral. This booklet provides information about funerals, legal requirements surrounding death, burial, Wills, estates, paperwork and financial assistance.

www.seniors-housing.alberta.ca/documents/Saying-Farewell-Dying-Process-Guide.pdf

♥ WHAT FUNERAL AND LEGAL SERVICES ARE AVAILABLE IN THE BOW VALLEY?

The table below shows only some of the available services. You can check other sources for additional legal services.

SERVICES	BUSINESS	CONTACT			
Funeral Services, Bow Valley					
	Bow River Funeral Service Russ and Wendy Reynolds	P: 403-678-4880 Canmore P: 403-762-2159 Banff 1508 Railway Ave., Canmore, AB www.bowriverfuneral.com			
Legal Services, Banff	Legal Services, Banff				
	Eric Harvey Barrister and Solicitor	P: 403-762-3438 E: info@lawbanff.ca 202, 216 Banff Ave., Banff, AB www.ericharvielaw.ca			
	Grover Froese Professional Corporation (Lisa Grover & Rod Froese)	P: 403-762-4206 E: banff@groverfroese.ca 200, 201 Bear Street, Banff, AB www.groverfroese.ca			
Legal Services, Canmore					
	Jessica L. Sturgeon	P: 403-678-9822 200, 729 10 St., Canmore, AB www.sturgeonlaw.ca			
	Grover Froese Professional Corporation (Lisa Grover & Rod Froese)	P: 403-678-4225 E: canmore@groverfroese.ca 209, 710 10 St., Canmore AB www.groverfroese.ca			
	Blackett Law (Don Blackett)	P: 403-678-0708 E: don@perrenblackett.com 221, 1001 6 Ave., Canmore, AB http://blackettlaw.com/			
	Tannis Naylor	P:403-678-5777 826 10 Street, Canmore, AB			

Write your questions, or notes, here.





9. INVENTORY OF HOSPICE PALLIATIVE RESOURCES, FIRST NATIONS, MORLEY

9. INVENTORY OF HOSPICE PALLIATIVE RESOURCES, FIRST NATIONS, MORLEY



The Stoney Nakoda First Nations (SNFNM), made up of the Bearspaw, Chiniki and Wesley bands, reside on the Morley reserve, just east of Canmore. The following hospice palliative services are accessible on the reserve, and all aspects of hospice palliative care are available. AHS = Alberta Health Services.

NAME OF SERVICE	SERVICE LOCATION	HOURS OF OPERATION	CONTACT INFO	DESCRIPTION OF SERVICE
Home Care Stoney Nakoda Nation	Stoney Health Centre (SHC) Stoney Nakoda First Nation Morley Reserve (SNFNM)	Mon-Fri 8:30am - 4pm	403-881-3920	Assessing and managing symptoms in the home; care planning and helping with goals of care; respite care; referral to other agencies e.g. Rural Palliative Care Consultation Team (Calgary Zone). Service providers may include RNs, LPNs, doctors, palliative care specialists, OTs and Social Workers.
Turning Point Mental Health Services	Chiniki College Morley Reserve	Mon-Fri 8:30am - 4pm	403-881-2877 info@stoneyhealth.com	Individual psychotherapy for adults and children for a range of suffering: • Anxiety and depression • Grief counselling • Critical incident stress management • Relationship and family conflict management
Emergency Medical Services (EMS)	SNFNM Reserve	24 hours a day, 7 days a week.	403- 385-0438 (AHS dispatch) Jeff Beddome (Nakoda EMS contact) 403-465-4654	Emergency medical support after SHC closes. EMS staff have Assess Treat and Refer (ATR) training.
Grief and Loss Circles	SNFNM Reserve Bearspaw Youth Centre See also Canadian Virtual Hospice: Indigenous Topics www.virtualhospice.ca	4-week program Tuesday: 2 PM to 1:30 PM The number of programs offered depends on success of fundraising efforts.	Elizabeth Short 403-660-5636 elizabeth@en-courage.ca Myrna Kootenay bp7.fcw@gmail.com	Group sessions in a circle. A Transition Model is used. Allows participants to gradually share their stories and explore their grief in a safe environment. All age groups are represented. An Elder is always present and translation is available as needed.
AHS Rural Palliative Care Consultation Team, Bow Corridor	SNFNM Reserve See also Palliative Care Toolkit for Aboriginal Communities www.archive.cancercare. on.ca/cms/One.aspx- ?portalld=1377&page- Id=325493	Can see patients Mon-Fri, 9 am to 5 m. All else, palliative care doctor on-call for tele- phone advice to Home Care & GPs.	Jill Uniacke MN CNS Work: 403-995-2714 Cell: 403-998-5458	A consult team that specializes in providing palliative care support to health care providers.

For off-reserve help, there is a First Nations liaison worker at the Canmore Hospital.

P: 403-678-7121

Write your questions, or notes, here.



THE BOOK OF LINKS

THE BOOK OF LINKS



The following is an inventory of electronic links that relate to each of the nine Sections of this guide. A companion document in hard-copy and pdf format is available.

INTRODUCTION

- a. The Palliative Care Society of the Bow Valley
 - www.palliativecarebowvalley.com/
- b. The Canadian Hospice Palliative Care Association:
 Model for the Role of Hospice Palliative Care During Illness
 - www.chpca.net/media/319547/norms-of-practice-eng-web.pdf (pages 5 & 7)
- c. The Canadian Hospice Palliative Care Association:
 - A Roadmap for an Integrated Palliative Approach to Care
 - www.hpcintegration.ca/resources/the-national-framework.aspx (pages 13 & 14)

1. DISEASE MANAGEMENT

- a. Information on Lou Gehrig's Disease
 - www.alsab.ca
 - www.als.ca
- b. Information on Chronic Obstructive Pulmonary Disease (COPD)
 - www.lung.ca/copd
- c. Information on advanced heart disease
 - www.heart.org
- d. Information and support on palliative and end-of-life care, loss and grief
 - www.virtualhospice.ca
- e. Alberta Health Services: Advance Care Planning
 - www.myhealth.alberta.ca/ Follow Patient & Family Green Sleeve Video
 - www.conversationsmatter.ca
 - conversationsmatter@albertahealthservices.ca
- f. Talk to your doctor
 - www.advancecareplanning.ca/making-your-plan/
 - www.theconversationproject.org
- g. Emergency Services: Assess, Treat, Refer (ATR) program
 - www.albertahealthservices.ca/info/Page14899.aspx
 - ems.palliative@albertahealthservices.ca
- h. Bow Valley doctor's offices
 - Banff www.alpinemedical.ca
 - Banff www.mtndocs.ca
 - Canmore www.bowrivermedicalclinic.com
 - Canmore www.facebook.com/canmoremedical
 - Canmore www.ridgeviewclinic.ca
 - Canmore www.threesistersob.com
 - Lake Louise www.llmc.ca
- i. Information on Medical Assistance in Dying (MAiD)
 - www.myhealth.alberta.ca/HealthTopics/Palliative-Care
 - www.AHS.ca/MAID

2. PHYSICAL CARE AND SUPPORT

a. Health care concerns

- Go to Support tab www.virtualhospice.ca
- All aspects of health care www.myhealth.alberta.ca
- Caregiver's Handbook www.hospicetoronto.ca/PDF/Acaregivershandbook_CHPCA.pdf

b. What to expect when you are dying

www.covenantcare.ca/media/6990/20150827-duclina-hospice-what-to-expect-when-a-person-is-dying.pdf

c. Important Care and Support

- Falling & Balance www.findingbalancealberta.ca
- Fatigue www.myhealth.alberta.ca/Alberta/Pages/cancer-fatigue.aspx
- Fatigue www.youtube.com/watch?v=YTFPMYGe86s
- Alberta Aids to Daily Living www.alberta.health.ca/services/aids-to-daily-living
- Seniors Blue Cross & Drug Benefits www.bluecross.ca
- As above www.alberta.health.ca/services/drugs-palliative-care
- Canmore Hospital www.albertahealthservices.ca/info/facility.aspx?id=1000951
- Banff Hospital www.albertahealthservices.ca/findhealth/facility.aspx?id=1772

d. Other Care and Support

- Sexual Health www.myhealth.alberta.ca/HealthTopics/Cancer-and-sexuality
- Dealing with Hair Loss www.myhealth.alberta.ca/health/pages/conditions.aspx?hwid=aa151672&#aa151675 www.cancer.ca (search for Find a Wig)
- Mouth & Dental Care www.myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=hw144414#hw144416

3. SOCIAL SERVICES AND SUPPORT

a. Communication

- www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Communication.aspx
- www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/Asked+and+Answered.aspx

b. Talking to families, spouse, professionals, children; caregiver support

- www.virtualhospice.ca/en US/Main+Site+Navigation/Home/Topics/Topics.aspx
- www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Providing+Care.aspx
- www.virtualhospice.ca/en US/Main+Site+Navigation/Home/Topics/Topics/Communication.aspx
- www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Communication/Tips+for+Talking+with+Your+Health+Care+Providers.aspx
- champlainpalliative.ca/for-caregivers-patients/support-for-caregivers/
- www.stlazarus.sjatraining.ca/registercertprog.php

4. SPIRITUAL CARE AND SUPPORT

a. Important Resources

- Spiritual Care at the Canmore Hospital www.albertahealthservices.ca/info/facility.aspx?id=1000951&service=1026227
- Mindfulness Meditation www.canmorehealthfoundation.com/mindfulness-program-meditation-and-yoga-for-stress/
- Nature & Grieving https://www.jpsmjournal.com/article/S0885-3924(16)30506-1/fulltext

b. Other Resources

- Threshold Choir www.thresholdchoir.org
- Death Café www.deathcafe.com
- Healing Pathways www.ralphconnor.ca/healing-pathway/healing-pathways
- McInnis & Holloway Library www.mhfh.com/grief-resources/grief-resources-library/grief-support



5. END-OF-LIFE CARE AND DEATH MANAGEMENT

a. Personal Directive

- www.alberta.ca/assets/documents/opgt-form-personal-directives-form-opg5521a.pdf
- www.ddsf.ca/ESW/Files/Personal Directive Form.pdf

b. Goals of Care

- MyHealth.Alberta.ca
- Conversations Matter

c. Enduring Power of Attorney and Wills

- www.cplea.ca/wp-content/uploads/MakingAnEnduringPowerOfAttorney.pdf
- www.alberta.ca/wills-in-alberta.aspx

d. Advance Care Planning

Advanced Care Planning

e. Planning Your Funeral

- www.seniors-housing.alberta.ca/documents/Saying-Farewell-Dying-Process-Guide.pdf
- www.canmore.ca/municipal-services/cemetery-services
- www.banff.ca/index.aspx?NID=432

f. Creating a Legacy

- www.hospicewaterloo.ca/resources/legacy-activities/
- www.cbc.ca/news/health/a-dying-patient-leaves-a-legacy-1.1044966

g. Prepare for Final Days

www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Final+Days.aspx

h. Other

- Medical Assistance in Dying (MAiD) www.canada.ca/en/health-canada/services/medical-assistance-dying.html
- Medical Assistance in Dying (MAiD)
 www.albertahealthservices.ca/assets/info/pf/if-pf-maid-fags-public.pdf

6. LOSS AND GRIEF

a. Information on grief support in the Bow Valley

• www.palliativecarebowvalley.com

b. General Sources of information

- Bob Glasgow Grief Centre in Calgary www.albertahealthservices.ca/assets/programs/ps-1026229-grief-support-calgary-brochure.pdf
- Sage Centre in Calgary www.hospicecalgary.ca/content/sage-centre-child-family-grief-services
- Canadian information on grief www.virtualhospice.ca
- www.mygrief.ca
- Children's Grief www.kidsgrief.ca
- Customs & Traditions in Times of Death and Bereavement www.2yrmnl1xwxgr2mtz1f435wih.wpengine.netdna-cdn.com/wp-content/uploads/Customs-and-Traditions-In-Times-of-Death-and-Bereavement_Intro.pdf
- McInnis and Holloway Grief Support Library www.mhfh.com/grief-resources/dr-wolfelts-grief-library

7. COMMUNITY SERVICES AND SUPPORT

a. Transportation

www.transparentconcierge.com/services/transportation/

b. Medical Supplies

www.canmeddirect.ca

c. General and Affordable Social Services

• www.canmore.ca/residents/family-community-services/emotional-support

d. Canmore Seniors Center

• www.canmoreseniors.org

e. Wellspring, Calgary (Living with Cancer)

www.wellspringcalgary.ca/what-we-offer/the-wellspring-experience/

8. ADMINISTRATION OF DYING

a. Financial Assistance

- Prescription drugs, diabetic supplies, ambulance services www.health.alberta.ca/services/drugs-palliative-care.htm
- Financial assistance for family caregivers www.canada.ca/en/services/benefits/ei/ei-compassionate.html
- Alberta Seniors Benefits Program www.seniors-housing.alberta.ca/seniors/seniors-benefit-program.html
- Special Needs Assistance for Seniors www.seniors-housing.alberta.ca/seniors/SNA-submit-claim.html
- Dental and Optical Assistance For Seniors www.seniors-housing.alberta.ca/seniors/dental-optical-assistance.html

b. Property Tax Deferral

• www.seniors-housing.alberta.ca/seniors/property-tax-deferral.html

c. Alberta Aides to Daily Living

• Income Support - www.health.alberta.ca/services/aids-to-daily-living.html

d. Other Assistance

- AISH (Assured Income for the Severely Handicapped) www.alberta.ca/aish.aspx
- Canada Pension Plan Disability Credit)
 www.canada.ca/en/employment-social-development/programs/pensions/reports/disability-benefits.html#h2.2
- Disability Tax Credit
 www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons disabilities/disability-tax-credit.html?utm_campaign=not-applicable&utm_medium=vanity-url&utm_
 source=canada-ca_disability-tax-credit
- Compassionate Leave for Caregivers www.alberta.ca/compassionate-care-leave.aspx
- Personal Directive www.ddsf.ca/ESW/Files/Personal Directive Form.pdf
- "I'm Dead: Now What?" Use this book to gather vital details about your contacts, legal matters, health, financial affairs and instructions.

 www.amazon.ca/Dead-Now-What-Information-Belongings/dp/1441317996/ref=sr 1 1?ie=UTF8&gid=

www.amazon.ca/Dead-Now-What-Information-Belongings/dp/1441317996/ref=sr_1_1?ie=UTF8&qid= 1526936466&sr=8-1&keywords=i%27m+dead+now+what

9. INVENTORY OF HOSPICE PALLIATIVE RESOURCES, FIRST NATIONS, MORLEY

- www.stoneyhealth.com
- See also Canadian Virtual Hospice: Indigenous Topics www.virtualhospice.ca/en_US/Utilities/Search.aspx?q=indigenous
- See also Palliative Care Toolkit for Aboriginal Communities www.archive.cancercare.on.ca/cms/One.aspx?portalld=1377&pageId=325493





BOOK AND MUSIC LIST

BOOK AND MUSIC LIST



We hope you find some helpful, hopeful strength from the material in the books and music below. They have been recommended by members of your community, who have been through what you are experiencing.

BOOKS

- 1. A Grief Observed: C. S. Lewis
- 2. Awake at the Bedside: Contemplative Teachings on Palliative and End-of-Life Care: Koshin Paley Ellison
- 3. Being Mortal, Medicine and What Matters in the End: Atul Gawande
- 4. Beyond Surviving: Cancer and Your Spiritual Journey: David Maginley
- 5. Closure on a Life: John Deeley
- 6. Cry, Heart, But Never Break (good for kids): Glenn Ringtved and Charlotte Pardi
- 7. Die Wise, A Manifesto for Sanity and Soul: Stephen Jenkins
- 8. Dignity Therapy: Final Words for Final Days: Dr. Harvey Chochinov
- 9. Duck, Death and the Tulip (good for kids): Wolf Erlbruch
- 10. Erasing Death: The Science That is Rewriting the Boundaries Between Life and Death: Sam Parnia
- 11. Everyday Grace: Carla Marie Carlson
- 12. Final Gifts: Maggie Callanan & Patricia Kelley
- 13. Final Journeys: A Practical Guide for Bringing Care and Comfort at the End of Life: Maggie Callanan
- 14. Full Catastrophe Living: Jon Kabat-Zinn
- 15. Graceful Passages, A Companion for Living and Dying (a book and 2-CD set): Michael Stillwater and Gary Malkin
- 16. Heading Outdoors Eventually Leads Within: Kathy & Craig Copeland
- 17. Healing Your Grieving Heart for Teens: 100 Practical Ideas: Alan Wolfelt
- 18. How We Die: Reflections of Life's Final Chapter: Sherwin Nuland
- **19. Into the Night:** Portraits of Life and Death (extraordinary video interviews) www.intothenightdoc.com/portraits-list/
- 20. Journeying Through Grief: Kenneth C. Haugk
- 21. Kitchen Table Wisdom: Rachel Naomi Renen
- 22. Man's Search for Meaning: Viktor Frankl
- 23. Michael Rosen's Sad Book (good for kids): Michael Rosen and Quentin Blake
- 24. My Father's Arms are a Boat (good for kids): Stein Erik Lunde and Øyvind Torseter
- 25. On Death and Dying:
 - What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families: Elizabeth Kübler-Ross
- 26. On Grief and Grieving: Finding the Meaning of Grief Through the 5 Stages of Loss: Elizabeth Kübler-Ross
- **27. Our Shared Journey:** A Guide to Manage Stress and Sleep; Guide on Grieving and Healing; Guide to Our Relationships: Canadian Hospice Palliative Care Association
- 28. Sands of the Well (poems about nature and the divine): Denise Levertov
- 29. Talking About Death Won't Kill You: Dr. Kathy Kortes-Miller
- 30. Tear Soup (good for kids): Pat Schwiebert, Chuck DeKlyen
- 31. The Art of Aging: A Doctor's Prescription for Well-Being: Shewing Nuland
- 32. The Emotional Facts of Life with Cancer: https://capo.ca/docs/bookletREVISED.pdf
- **33. The Five Invitations:** Discovering What Death Can Teach Us About Living Fully: Frank Ostaseski (Co-founder of the Zen Hospice Project)
- 34. The Handbook of Hospice Care: Robert Buckingham

- 35. The Heart and the Bottle (good for kids): Oliver Jeffers
- 36. The Mourner's Dance: What We Do When People Die: Katherine Ashenburg
- 37. The Top Five Regrets of the Dying: Bronnie Ware
- 38. Tuesdays with Morrie: Mitch Albom
- 39. Visions, Trips & Crowded Rooms: Who & What You See Before You Die: David Kessler
- 40. Waking the Spirit. A Musician's Journey Healing Body, Mind, and Soul: Andrew Schulman
- 41. What Dying People Want: David Kuhl
- 42. When Breath Becomes Air: Paul Kalanithi
- 43. Words to Love By: Mother Teresa

MUSIC

- 1. Breaking Through the Mist: Exploring Nature with Music: Gordon Gibson
- 2. Classical Chillout: Various Artists
- Crossing Over: Skylark
 Deep Peace: Bill Douglas
 Escapes: Various Artists
- 6. Ešenvald, Northern Lights: Trinity College Cambridge Choir
- 7. Essential Choral Classics: Various Artists
- 8. Eventide: Voces8
- 9. Evocation of the Spirit: Robert Shaw & Robert Shaw Festival Chorus
- 10. Gorecki Symphony No. 3 (Symphony of Sorrowful Songs): Dawn Upshaw & London Sinfonietta
- 11. Graceful Passages, A Companion for Living and Dying (a book and 2-CD set):
 Michael Stillwater and Gary Malkin
- 12. Joyous Light: Isabel Bayrakdarin
- 13. Lauridsen, Choral Works: Morten Lauridsen
- 14. Light of Gold: Eric Whitacre
- 15. Magnificat: Chanticleer
- 16. Movie Adagios: Various Artists
- 17. Native Spirit: Traditional Native American Flute: Various Artists
- Requiem: Michael Hoppé
 Returning: Jennifer Berezan
- 20. Sacred Treasures 4, Choral Masterworks, Quiet Prayer: Various Artists
- **21. Solitude:** Michael Hoppé **22. Spiritlands:** John Huling
- 23. Spiritual Songs, Hildegard von Bingen: Sequentia
- 24. Tapestry: Michael Hoppé
- 25. The Most Relaxing Classical Music: Various Artists
- **26. Unspeakable Grace:** Gary Malkin **27. Violin Adagios:** Various Artists
- 21. Violiti Adagios. Various Artists
- 28. Vivaldi Four Seasons: Enrico Onofri 29. Yo-Yo Ma Plays Ennio Morricone: Yo-Yo Ma
- 30. Zamfir Gold: Zamfir (Pan Flute)





INTERPROFESSIONAL EDUCATION & LEARNING

INTERPROFESSIONAL EDUCATION AND LEARNING



The following are electronic links for health care providers, in the area of educational opportunities:

- 1. Pallium Canada: LEAP (Learning Essential Approaches to Palliative Care).
 Palliative care education for all care providers and mobilization of compassionate communities.
 www.pallium.ca
- 2. Canadian Nurses Association: Certification in Hospice Palliative Care www.cna-aiic.ca/en/certification/get-certified/certification-nursing-practice-specialties
- 3. Cumming School of Medicine, University of Calgary: Certificate in Palliative Care www.ucalgary.ca/palliativemedicine/application-process
- 4. Mary O'Connor Palliative and Hospice Care Conference:
 Annual conference in Calgary for health care providers.
 www.maryoconnorconf.wixsite.com/maryoconnor2018
- **5. Canadian Hospice Palliative Care Association:** Annual Learning Institute www.conference.chpca.net
- **6.** International Congress on Palliative Care: Montreal, Quebec www.palliativecare.ca
- 7. Canadian Society of Palliative Care Physicians: Advanced Learning in Palliative Medicine Conference www.cspcp.ca/news-events
- **8. Alberta Hospice Palliative Care Association:** Annual Palliative Care Roadshow www.ahpca.ca/2018-alberta-hospice-palliative-care-association-roadshow
- 9. Soul Passages: Holistic Death Network www.soulpassages.ca/programs-and-courses/death-education/
- **10. Covenant Health:** Annual Palliative Education and Research Days www.covenanthealth.ca/innovations/palliative-institute/annual-palliative-education-research-days
- **11. Alberta Health Services:** Palliative Volunteer Course www.albertahealthservices.ca/info/Page15276.aspx
- **12. Canadian Virtual Hospice:** Courses and Conferences www.virtualhospice.ca
- 13. Alberta Health Services, Calgary Zone. Bob Glasgow Grief Support Centre in Calgary: Workshops on Grief, Advance Care Planning etc. www.albertahealthservices.ca/assets/programs/ps-1026229-grief-support-calgary-brochure.pdf
- **14. Canadian Association of Schools of Nursing**www.casn.ca/wp-content/uploads/2014/12/PEOLCCompetenciesandIndicatorsEn.pdf
- **15. Alberta Health Services. Provincial Palliative and End-of-Life Care Newsletter** www.albertahealthservices.ca/assets/info/hp/peolc/if-hp-peolc-newsletter-2018-04.pdf
- 16. Alberta Health Services: Alberta Provincial Framework, Palliative and End-of-Life Care www.albertahealthservices.ca/assets/info/seniors/if-sen-provincial-palliative-end-of-life-care-framework.pdf
- 17. The Pallium Palliative Pocketbook, A Peer-Reviewed Reference Source, 2nd Edition (2016) www.pallium.ca/product/pallium-palliative-pocketbook-2nd-edition
- **18. 99 Questions (and more) About Hospice Palliative Care:** A Nurse's Handbook, 3rd Edition. www.palliative.org/NewPC/_pdfs/education/99QuestionsEbook2013.pdf



CALGARY HOSPICES AND RESOURCES





NAME OF ORGANIZATION	CONTACT INFORMATION	COMMENTS	
HOSPICES			
Hospice Central Access	403-944-1614 403-955-8011 (grief support) 1. www.albertahealthservices.ca/info/page13766.aspx 2. www.albertahealthservices.ca/assets/programs/ps-hospice-calgary-brochure.pdf	Hospice referral centre	
Agapé Hospice	403-282-6588 1302 8 Avenue NW, Calgary, AB T2N 1B8 information@agapehospice.ca	Residential beds (20)	
Chinook Hospice	403-258-0040 1261 Glenmore Trail SW, Calgary, AB T2V 4Y8	Residential beds (14)	
Dulcina Hospice	587-230-5500 110 Evanspark Manor, NW Calgary, AB T3P 0B1 SMM.Admin@covenantcare.ca	Residential beds (26)	
Foothills Country Hospice	403-995-4673 322001 32 Street E, De Winton, AB T0L 0X0 executivedirector@countryhospice.org	Residential beds (8)	
Rosedale Hospice	403-284-5195 920 7a Street NW, Calgary, AB T2M 3J4 rosedale.hospice@hospicecalgary.com	Residential beds (7) Only accepts cancer patients.	
Rotary Flames House for Children	403-955-5500 18 Childrens Drive NW, Calgary, AB T3B 6A8 heather.hunter@ahs.ca	Residential beds (8)	
Carewest Sarcee Hospice	403-685-6460 3504 Sarcee Road SW, Calgary, AB T3E 2L3	Residential beds (15)	
Southwood Hospice	403-252-0620 211 Heritage Drive SE, Calgary, AB T2H 1M9	Residential beds (24)	
OTHER SUPPORT			
Alberta Health Services Health Link	811 and 403-955-8011 (24 hours a day, 7 days a week)	Health advice and grief support care	
Sage Center	403-263-4525 1245 70 Avenue SE, Calgary, AB T2H 2X8 info@hospicecalgary.com	Grief counselling, children + teens	
Bob Glasgow Grief Support Centre, AHS	403-995-8011 1820 Richmond Road SW, Calgary AB T2T 5C7 www.albertahealthservices.ca/info/facility.aspx?id=6&ser- vice=1026229	For adults 18+	

NAME OF ORGANIZATION	CONTACT INFORMATION	COMMENTS
Bridgeland Seniors Health Centre	403-955-1674 1070 McDougall Road NE, Calgary, AB T2E 8B8 www.albertahealthservices.ca/info/facility.aspx- ?id=1033004&service=1604	Family Care-Giver Centre
Wellspring Calgary	403-521-5292 1404 Home Road NW, Calgary AB T3B 1G7 www.wellspringcalgary.com/index.asp	Inform, support, empower those living with cancer.
McInnis & Holloway	403-243-8200 www.mhfh.com/grief-resources/dr-wolfelts-grief-library	Grief Library

