



When You Are Facing a Life-Limiting Diagnosis

*Resources and Services
for You and Your Family*

Nelson, BC

Resources and Services for Supportive and Palliative Care

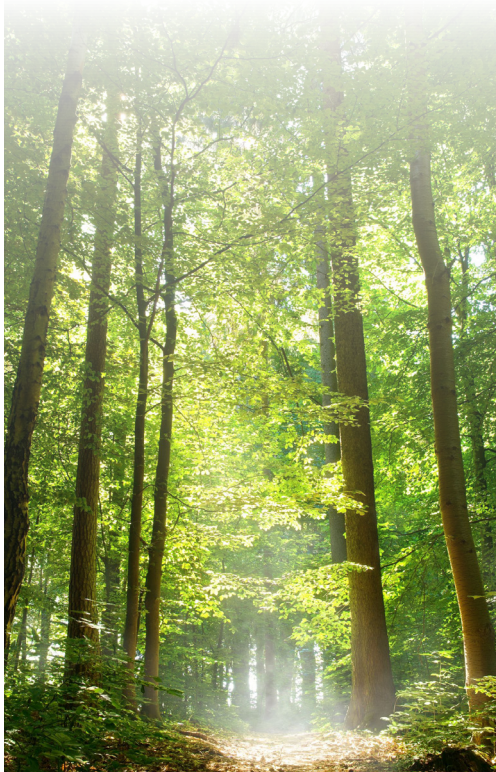
Have you, or someone you love, recently been given a life-limiting diagnosis?

It may feel like a discouraging day when you have been told your health is changing. You may be asking yourself some very significant questions:

- What do I do now?
- Am I going to lose control of my life, or my body?
- What does 'life-limiting' mean in terms of how much time I have left?
- How will I manage if my illness changes?

At this point you may not even have words to express your concerns. You may feel like you are on a physical, emotional and spiritual 'roller coaster'.

A life-limiting diagnosis indicates that you are moving into a stage where you will be receiving treatment as necessary, as well as supportive and palliative care that will provide you with comfort and help you to manage your changing condition. The word 'palliative' is not only used to refer to dying. Now a palliative approach recognizes that a life-limiting illness often starts months to years prior to the end of life. This is a part of life's journey and supportive services during this time aim to significantly improve your function and quality of life and help you live well.



Resources and Services for Supportive and Palliative Care

You will be connecting with your local palliative care team, which allows you to access services that will provide you with professional help and financial coverage for many of the supports you may need over time. Their use of a palliative approach will minimize any symptoms you have and provide care that is grounded in your values and aligns with your preferences.

It is normal to experience uncertainty at this stage of life. Be kind to yourself and take the time you need to reflect on what you value most. It is an opportunity to set some goals for yourself and your family and to act on them. It is also a time to learn about all the resources available in our community to support you to be able to live as fully as possible during your journey.

We encourage you to take control and remember that this is your life to live. Your palliative team is right alongside you, supporting you all the way.

Sincerely,

Dr. Lilli Kerby, Dr. Lisa Sawyer, and Dr. Trevor Janz
Palliative Care Physician Leads, Kootenay Boundary



What Can I Do Right Now?

- Think about who in your family needs to know about your changing health. Sit down with them and clearly tell them what you know so far. They are your immediate support system. Communicating difficult news takes a lot of energy but clear communication eases anxiety.
- Develop a list of the unanswered questions you have that can be discussed with your health care providers when you see them next.



What About the Future? “Putting My House in Order”

- Think about what is most important to you now. Document your goals.
- Develop an Advance Care Plan (ACP). This will state your exact desires in terms of medical intervention – what you will allow and what you don’t want. Give a copy to your health care providers and your immediate family members. This form states your wishes clearly. The form is available at: www.advancecareplanning.ca or speak to someone at the Hospice Society (250-352-2337) or the Palliative Social Worker for assistance (250-354-2394).
- Are there any financial or legal issues you need to attend to? (for example: signing authority, Power of Attorney & Representation Agreement, property titles, gifting assets, etc.)
- Look around your home. On days when you don’t feel well are there obstacles to accessing things or challenges for your mobility? What practical changes could be made in your home that would make daily life more manageable (for example, using a different bedroom; bathroom aides)?
- Set a small daily goal. This gives you something to strive for and focus on for the day.

✓ **Check each one off as you work through the list**

If you need help with any of these things, ask your palliative team (references on the back page) or draw on support from your family and friends.

Things to discuss with your Family Doctor or Nurse Practitioner (NP)

- If my symptoms get worse, how will they be managed and who will manage them?
- What can you tell me about how my illness might change in the near and more distant future?
- Although you can’t give me an exact timeline, could you tell me how much time I might have left in years or months so I can plan ahead?
- If I am too unwell to come and see you in your office, do you make house calls?
- Do I always have to see you in your office or could we book a ‘phone appointment’ to discuss my changing care needs?
- What will happen if I need medical care (for example, symptom management) and you are out of town or your office is closed?
- My personal Advance Care Plan and any end-of-life wishes.

Let your Family Doctor or Nurse Practitioner (NP) know how much detailed information you hope to receive during your palliative journey (do you prefer a lot of details or just an overview of things?). Your Family Doctor will have a conversation with you about the important decisions you will need to make about types of treatments or interventions in the future.

Most primary care providers want you to bring a close family member or other support person along to each medical appointment. It helps to have someone else hear the conversation as well, confirm what you have been told, and to take notes.

Palliative care can be provided in many different settings. Your health care providers will be able to explain the various options for you. If you have questions about Medical Assistance in Dying (MAiD), please speak to your Family Doctor or NP or visit here for more information: <http://bit.ly/BC-MAiD>.

Resources to Support You and Your Family in the Nelson Community of Care



Any or all of these services and resources may be integrated into your care as needed. Palliative Care provides you support to live with quality of life.

Information for the Future

When your Family Doctor or NP feels it is appropriate, there are numerous Palliative Benefits to support you and your family as your illness progresses. More information is available on the Interior Health website for palliative care:

<https://www.interiorhealth.ca/YourCare/PalliativeCare/>

BC Palliative Benefits

BC Palliative Benefits are available to permanent residents of BC (of any age) who wish to receive palliative care at home or those who are facing a life-threatening disease. There is no charge for these BC palliative benefits.

What is covered?

- Home Care nurses who will monitor your condition, provide treatments as ordered by your Family Doctor, and help manage your symptom control.
- Palliative medications (prescription and some over-the-counter pharmaceuticals). These are drugs used for symptom control and improved quality of life.
- Medical supplies enabling palliative care at home. Examples: an electric hospital bed, drug delivery pumps, mobility aides (walkers, wheelchairs, lifts), bathroom safety aides, wound care supplies, medication administration equipment, incontinence supplies.
- Home Health Aide assistants up to 4 hours per day to help with personal care or family respite time.
- 'After Hours Palliative Nursing Service' Line
- Trained Community Paramedics are available for palliative support in some locations.



Your Family Doctor or NP must certify you meet the criteria for the program and then submit an application on your behalf when you are eligible. More information is available at: <http://bit.ly/govbcpalliative>

Federal Compassionate Benefits

Compassionate Care Benefits (CCB) are Employment Insurance (EI) benefits paid to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (six months).

The goal of the CCB is to enable employees to take a temporary secured leave from work to provide care or support to a gravely ill family member at risk of dying.

The CCB program adopts a broad view of those considered to be a 'family member.' Program recipients can care for a gravely ill: (1) family member; (2) spouse or common-law partner's family members; or (3) person who is considered 'like' a family member (for instance a close friend or neighbour).

Applications for this program are made through Service Canada Centers. More information is available at: <http://bit.ly/fedcarebenefits>



Resources and Services for Supportive and Palliative Care

Who Do I Call When I Need Help? (Fill this in with your care team's numbers)

With management of my symptoms	<i>Your local pharmacist or Home Health Nurse*</i>
Have questions about the drugs I am taking and the side effects I am having	<i>Your local pharmacist Number:</i>
If I need my medications delivered to my home when I can't get out	<i>Your local pharmacist Number:</i>
Have questions about how to organize my medications or take them properly*	<i>Your Home Health Nurse Number: 250-352-1433</i>
If I need help with bathing or personal care*	<i>Your Home Health Nurse Number: 250-352-1433</i>
If I require help with my finances or paperwork applications*	<i>Palliative Social Worker Number: 250-354-2394</i>
If I need help filling out an Advance Care Plan	<i>Palliative Social Worker* Number: 250-354-2394 Nelson Hospice Society Number: 250-352-2337</i>
If I am having trouble with food intake	<i>Your Family Doctor or Nurse Practitioner can refer you to a Dietitian or Occupational Therapist</i>
If I need mobility aides	<i>Your Family Doctor, NP or Home Health Nurse can refer you to an Occupational Therapist</i>
When I need help deciding where I want to spend my last days	<i>Your Family Doctor, NP or Home Health Nurse Number:</i>
When I need help but the Home Health Office is closed*	<i>A Home Health Nurse will connect you with the After Hours Palliative Nursing Service Line Number:</i>
If my family is getting tired and needs more help with my care or some time off*	<i>Your Home Health Nurse Number: 250-352-1433</i>
If I need support when I have to travel out of area for treatments*	<i>Palliative Social Worker Number: 250-354-2394</i>
If I need to talk to someone about spiritual matters	<i>Your pastor, priest or spiritual advisor Number: or call the Nelson Hospice Society Number: 250-352-2337</i>
If I am feeling lonely or scared and would like someone to visit with me	<i>Nelson Hospice Society, Social Worker, or Crisis Line Number:</i>
If I need peer support during my illness	<i>Nelson Hospice Society Number: 250-352-2337</i>
Support for death at home & after death care	<i>Nelson End-of-Life Society Number: 250-509-1617</i>

*These services are available when you are on Palliative Benefits or have a Community Case Manager. Contact Home Health at 250-352-1433 for more details.

More excellent resources, including palliative topics; caregiving tips; blogs for patients and families; expert advice and stories, can be found on the Canadian Virtual Hospice Website: <http://bit.ly/CVH-website>

Please consider sharing your thoughts on this resource by completing this survey: <http://bit.ly/pallcaresurvey>