

A message from your Palliative Care Resource Team

October 2024



How can individuals feel more prepared and involved in their illness journey?

Many individuals diagnosed with an advancing life-limiting illness feel 'in the dark' or overwhelmed throughout their illness journey. Empowering and supporting individuals to participate in decisions affecting their health ensures they feel respected, included and acknowledged by health care providers (Wakefield et al., 2018).

Empowerment refers to a process that supports hope and personal agency; individuals understand and choose what role they want to play in their health, and have access to the knowledge/skills/support required to navigate the health care system and participate in care that best reflects their wishes (Wakefield et al., 2018; WHO, 2021). Health care providers play an important role in supporting patient participation by addressing power imbalances that serve to inhibit personal agency (WHO, 2021).

Health Canada has created a resource for individuals to help them access a palliative approach to care earlier in their illness journey. Asking health care providers key questions early can help individuals understand their illness, what to expect and how to best prepare for future changes (Health Canada, 2023).

Questions to ask your health care team:


What does it mean to have a this serious illness?

What can I expect now and in the future?

How can I prepare for what might come next?

In this issue:

- Introduce 2 new resources from **Health Canada** that support patient empowerment and improved the experience of illness:
- Introduce the **Waiting Room Revolution** resources for individuals living with a life-limiting illness
- **7 keys for navigating a life-changing diagnosis**
- Free Public YG Learn Modules
- Upcoming at Hospice Yukon



What to do when facing a serious illness:
3 sets of questions to ask your health care team

Receiving a diagnosis of a serious illness can be overwhelming. Often people don't know what the journey will look like. However, there are things you can do to help you communicate with your health care team. For example, you and those closest to you can ask key questions to make sure you understand your illness.

Wakefield, D., Bayly, J., Selman, L. E., Firth, A. M., Higginson, I. J., & Murtagh, F. E. (2018). Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: A systematic review using critical interpretive synthesis. *Palliative medicine*, 32(8), 1288–1304. <https://doi.org/10.1177/0269216318783919>

World Health Organization. (2021). Voice, agency, empowerment—handbook on social participation for universal health coverage. <https://www.who.int/publications/i/item/9789240027794>



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Making serious illness conversations easier: 3 questions health care providers can ask themselves

[Health Canada](#) has also created a resource for health care providers (HCPs) to help make difficult conversations about serious illness easier and help individuals participate and guide their own care earlier in their illness trajectory.

Asking these questions early supports [a palliative approach to care](#); individuals living with an advancing life-limiting illness are supported to participate in their own care earlier in their illness trajectory. Patient empowerment also results in strengthened relationships with providers and services (Wakefield et al., 2018).

To learn more about serious illness and palliative care in Canada visit canada.ca/palliative-care

3 Questions to ask yourself that make difficult conversations about serious illness easier

Talking with your patients about their serious illness is not easy

We all have had that uncomfortable feeling of not knowing what to say or when to say it. Regardless of your role, ask yourself these three questions.

1 Is a treatment or care decision needed?

The answer directs you to the purpose and outcomes of the conversation.

If yes, then you are supporting **deciding**. Make sure illness is understood and decisions align with a person's values and goals.

If no, then you are helping with **preparing**. Prepare a patient and substitute decision makers (SDM) for progressing illness and future decision-making.

2 What do they know?

Up to **70%** of people do not understand that their serious illness cannot be cured and will progress over time. Exploring what the person understands about their illness helps you to know how much and what kind of information to offer.

3 What matters to the person?

There is clear evidence that values and goals guide **as few as 10%** of clinician recommendations. Helping your patient express their values and goals will keep the person at the centre of the decision.

Benefits – When a seriously ill patient and their substitute decision makers (SDM) are prepared, outcomes are better, distress is less and clinicians have greater professional satisfaction.

Project ECHO Free Online Webinar for Health Care Providers

“Health care providers know that integrating an early palliative care approach is difficult, in part because palliative care is associated with death and dying. As a result, palliative care is more commonly delivered at end of life or the “11th hour.” The presenters have talked with thousands of patients and families to uncover 7 keys to enable an early approach to palliative care.” [7 Keys to Delivering Palliative Care Upstream: What We Learned From 1,000 Patients and Families](#)

Seow, H., & Winemaker, S. (2021). The waiting room revolution. <https://www.waitingroomrevolution.com/>

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7 KEYS for navigating a life-changing diagnosis



1. Walk Two Roads

Balance staying positive while also seeking honest, accurate information. This helps you stay hopeful and grounded to reality.

ACTION

Ask yourself what you are hoping for and what you need to plan for just in case?

2. Zoom Out

Every illness has a known pattern to it. Understanding this storyline gives you a birds-eye view of where you are at in your illness and the long view.

Ask your provider "What will my illness look like over time? What can I expect along the way?"

ACTION



3. Know Your Style

Your unique way of being will have as much impact on your illness experience as the illness itself. Harness information about your style to gain more control.

ACTION

Reflect on your tendencies when facing stressful situations and how those might apply in your illness.

4. Customize Your Order

At times you may want to tailor your care to match your values. Use your values and preferences to guide your decisions throughout your illness.

Ask yourself what do you value most?

ACTION



5. Anticipate Ripple Effects

Your inner crew (e.g. family and caregivers) will have a parallel illness journey. Their lives will be affected in multiple ways.

ACTION

Consider what support you need from your inner crew. Encourage them to get information and support too.

6. Connect the Dots

You and your inner crew need to play a central role in co-ordinating information. This enhances continuity and safety, especially at transition points

Ask yourself who will be the manager of your journey?

ACTION



7. Invite Yourself

Initiate conversations with your healthcare team. Don't assume no news is good news. Passive, polite patients are encouraged to be respectfully assertive.

ACTION

Ask questions and seek the information you need so you can make informed decisions.

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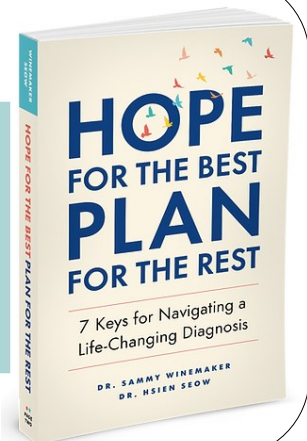
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The Waiting Room Revolution



Two Canadian palliative care specialist MDs have created 2 helpful resources for individuals living with a life-limiting illness to support a more positive illness experience right from diagnosis. With real-life stories, tips, and exercises, their [podcast](#) and [book](#) aims to empower individuals with practical tools and knowledge to navigate the health care system with confidence and clarity (Seow & Winemaker, 2021).

To learn more visit www.waitingroomrevolution.com



Free Public YG Learn Education Modules

- Introduction to Palliative Care Service Delivery in the Yukon:

<https://yglearn.gov.yk.ca/palliative-care/3806>

- Yukon Advance Care Planning:

<https://yglearn.gov.yk.ca/palliative-care/3031>

- Victoria Hospice Palliative Performance Scale (PPSv2):

<https://yglearn.gov.yk.ca/palliative-care/3203>

- Edmonton Symptom Assessment System

<https://yglearn.gov.yk.ca/palliative-care/1866>

Important Dates

October is Breast Cancer Awareness Month—Canadian Breast Cancer Foundation - <http://www.cbcf.org/>

National Children's Hospice Palliative Care Day—October 12th, 2024 <https://www.chpca.ca/campaigns/hpcfchildren/>

National Grief and Bereavement Day—November 21st, 2024 <https://www.chpca.ca/campaigns/bereavementday/>

World Hospice and Palliative Care Day-October 12th <https://thewhpc.org/world-hospice-and-palliative-care-day/about-2/>

Upcoming at



November 1	Loss in the Workplace
November 13	Living with Loss
December 12	Lights of Life Ceremony

Details at www.hospiceyukon.net/events

The Palliative Care Resource Team

How does the Palliative Care Resource Team (PCRT) support Yukoner's living with a life-limiting illness and the people caring for them?

- We connect individuals to existing services and programs.
- We provide links to resources and information regarding a variety of topics, including: advance care planning and caregiver specific supports.
- We provide public education sessions.

How does PCRT support Yukon health care providers?

- We assist with health systems navigation.
- We support care transitions and discharge planning.
- We offer symptom management consultation.
- We link health care providers to best practice resources, tools and information.
- We facilitate and provide palliative care education for health care providers.

For more information about the palliative care resource team and our services please contact us at:

Email: palliativecare@yukon.ca

Phone: (867) 667-9380

Stay tuned for an update to our website at <https://yukon.ca/en/palliative-care>