

Making Choices for Caregivers

When someone has advanced cancer they may be in their last stages of life. It is their journey and they might not want to burden or upset others by talking about their illness. However, their dignity and choices should be respected.

It is important that their wishes be known so that they can be followed as much as possible. For example, they might want to have a certain photo album, music or other things that would be comforting. Someone could ask them what to bring to the hospital to make them feel more at home.

The person should also identify which family members they want involved in their care. This way, health care providers will know who to talk to about the person's health and who to ask about treatment decisions.

If the person's condition worsens, they might not want to be in hospital; they might want to spend their final days at home. If the person wants this, their family should talk about whether they will be prepared to care for them at home. Family members might want to speak to their community health workers (e.g. home support worker) about making arrangements for available services and supports. It will be important for the family members to know what they are committing to and where to get support and help. Depending on where they are located, these might include hospice programs, volunteer programs, nursing care, personal support care or other outreach support.

In Your Community

For more information about palliative care, talk to your health care provider (e.g. doctor, specialist, or nurse) or community health worker (e.g. home support worker).

Your health care provider or community health worker can also provide more resources with information and support, including information from Cancer Care Ontario and the Canadian Cancer Society.



Understanding the Diagnosis for Patients and Caregivers



What is Palliative Care

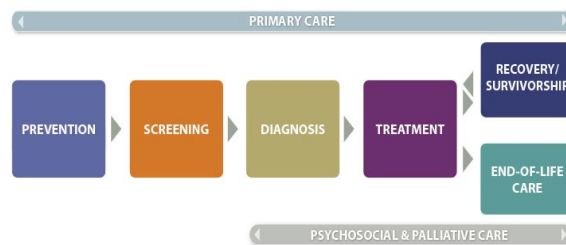
Palliative care is about comforting a person and offering support. Some people call it “comfort care”. Palliative care can be provided as soon as a person is diagnosed with cancer and at any stage of their cancer or if they have another illness that is unlikely to be cured. It can begin whether the person is still taking treatments or not. Palliative care can help ease and comfort someone in their journey, and can provide support and aftercare for their family.

“Palliative care” is a term that is not commonly heard in First Nations, Inuit and Métis communities. To First Nations, Inuit and Métis people, palliative care means:

- Kind, compassionate care that is given with understanding and respect
- Care that relieves a person’s pain and symptoms for the best quality of life
- Care that honours a person’s spiritual beliefs, traditions and customs
- Care for the whole person and support for the whole family

The cancer journey

Better cancer services every step of the way



Diagnosis

When a doctor diagnoses someone’s cancer to be at an advanced stage, it means that the cancer probably cannot be cured. It might also be called metastatic, progressive or terminal cancer. At this point there is nothing more that can be done medically to cure the illness, although some treatments can help make a person more comfortable.

At this time, health care providers (doctors, specialists, nurses and others) may be focused on setting up treatments and checking on how the person responds to the treatment. The person and their family can often be in shock and feel overwhelmed. Even if they receive a lot of information, they might find it hard to believe and understand what is happening.

The person who is ill might want to have someone attend appointments with them. It can be very helpful to have a family member or friend there to ask questions, have information explained, to keep notes and copies of tests and write down appointment schedules.

“It’s their journey, no-one else’s.”

Communicating with Health Care Providers

Sometimes in First Nations, Inuit and Métis communities we might not want to ask questions of our health care providers; we might feel it is disrespectful, or we might be afraid to ask questions. When someone is ill it is their right to have the information they need about their health. It might be helpful to have a list of questions to ask the doctors or specialists.

Examples of questions for the **patient** to ask:

- Can anything be done to slow down or stop my illness? (eg. treatments, clinical trials)
- What are the treatments like (e.g. does radiation hurt)? What are the side effects?
- How long do the treatments usually last for (e.g. length of time)
- What will happen if I don’t do the treatments?
- If I choose to see a healer, how does this affect the treatments you are recommending?
- What support services are available to me, either in the hospital or the community?

Examples of questions for the **caregiver** to ask:

- What do you think will happen to them next?
- Is their illness terminal? How much time do you think they have?
- If they choose to stay at home, how can we get help and support?
- What should I be concerned about or look for as a caregiver?
- What support services are available to us, as caregivers either in the hospital or the community?