

Understanding Palliative Care for Indigenous Peoples



What is Palliative Care?

Palliative care is a type of care and support for individuals living with a life-changing illness and their families. Palliative care can sound scary because it is sometimes confused with end-of-life care. Palliative care can actually be provided at any point on a person's illness journey.

Palliative care is about helping people live well by relieving their symptoms and providing emotional, social, and spiritual support when needed.

Palliative care can mean:

- 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

Who Provides Palliative Care?

Many people can be involved in providing palliative care, including family, friends, doctors, nurses, social workers, personal support workers, Elders, Traditional Healers, and community-based health care providers. It can be provided in different locations, including at home, at a long-term care centre, on the land, in Ceremony, or at a hospital.

It is important for you to choose which family members or friends you want involved in your care. That way, your health care providers will know who they can talk to about your health and treatment decisions.

It is also important to remember that your illness journey is your own journey, and your choices should be respected. Together with your health care providers and family, you can make decisions that are best for you.

Talking with Health Care Providers

It can be overwhelming to ask health care providers questions about your health and treatment options. Writing down a list of questions to ask might be helpful. You can also bring someone who you trust with you to help you remember the information shared.

It is your right to have the information you need to make decisions about your health.

Questions you can ask:

- What can we expect to happen next?
- Can anything be done to slow down or stop my illness?
- What are the treatments like? What are the side effects?
- How long do the treatments usually last for?
- What will happen if I don't do the treatments?
- What support services are available to me, in the hospital or the community?
- Do you have an Indigenous Healing Space in the health care facility?
- How can I access Traditional Ceremonies in the health care facility?
- Are there any translation services available?
- Do I have to leave my community for treatment?
- Are there any supports for grief and bereavement?

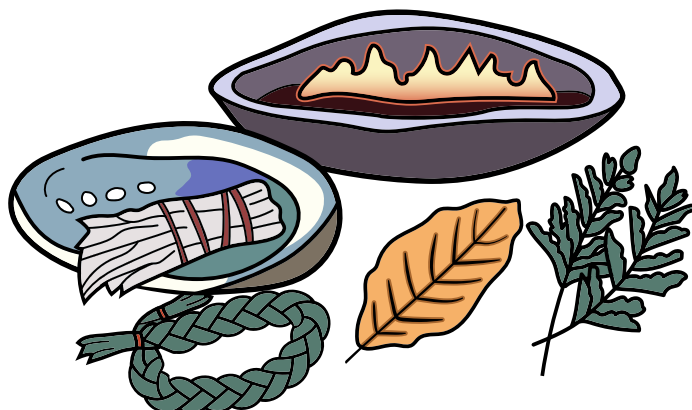
Questions someone supporting you can ask:

- What is the usual progression of the kind of illness that my family member or friend has?
- If they choose to stay at home, how can we get help and support (e.g., training, financial assistance, home and community care workers, etc.)?
- What should I be concerned about or look for as a caregiver?
- Who will be a part of their health care team and what does each person do?
- What support services are available to us, as caregivers or family members, in the hospital or the community?
- What is the visitor policy?
- Do caregivers have access to an Indigenous Healing Space in the health care facility?
- What is the health care facility's Traditional Practices Policy?
- Who should I call with questions or concerns during business and non-business hours?

Cultural Safety

Indigenous peoples have the right to culturally safe health care, including palliative care.

Culturally safe health care is free of racism and discrimination where all interactions are rooted in respect. When health care is culturally safe, Indigenous peoples are equal partners in their care and all interactions are physically, mentally, emotionally, and spiritually safe.



Submitting a Complaint

If an experience or interaction is not culturally safe for you or someone you are caring for, you can submit a complaint. The process of submitting a complaint can be an intimidating process for many and emotionally difficult. Reach out to someone you trust to help support you.

- The first step is to file a complaint through the health organization's own process where the experience or interaction occurred. This makes the health organization aware of the concern and provides the opportunity for the organization to address the concern directly.
 - For example, in a hospital this would be the hospital's patient relations department.
- If you or the person you are caring for are not happy with the way the health care organization is responding to the complaint, or you don't feel that the issue has been resolved, Patient Ombudsman may be able to help.
 - Patient Ombudsman is an independent and impartial agency that helps resolve complaints from patients, long-term care home residents, or their caregivers about experiences in Ontario's hospitals, long-term care homes, home care, and community surgical and diagnostic centres. Patient Ombudsman has a designated team to support Indigenous patients, residents, and caregivers.
- You or the person you are caring for may not feel comfortable filing a complaint with the health organization where the incident occurred because of past experiences or fear that quality of care may be impacted. If this is the case, you can contact Patient Ombudsman to ask about your options or discuss your concerns.

You can contact **Patient Ombudsman** by phone at **888-321-0339** or visit patientombudsman.ca for more information.

Need this information in an accessible format?

1-877-280-8538, TTY 1-800-855-0511, info@ontariohealth.ca

Document disponible en français en contactant info@ontariohealth.ca.

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Resources

Indigenous Cancer Navigators can support you and your family along the cancer journey.

» cancercareontario.ca/en/find-cancer-services/indigenous-navigators

Indigenous Patient Navigators can support you and your family to navigate the health care system. Ask your health care provider if there is an Indigenous Patient Navigator in the hospital where you will be receiving care.

Canadian Virtual Hospice Living My Culture is a platform where people from different cultures share their stories and wisdom about living with illness, end-of-life, and grief.

» livingmyculture.ca/culture/

Centre for Education and Research on Aging & Health has many resources for Indigenous caregivers and other resources.

» cerah.lakeheadu.ca/resources/indigenous-health

Hope for Wellness is a free 24/7 culturally safe resource to support you and the people you care about with mental health.

» Call **1-855-242-3310** or connect to the online chat at hopeforwellness.ca

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