PALLIATIVE CARE IN FIRST NATIONS, INUIT AND MÉTIS COMMUNITIES

Things to Remember

Do not assume that the person understands the medical terms and information they are receiving. Without a clear explanation, individuals can misunderstand what treatments such as radiation might do to them. These terms need to be explained clearly to the person and their family.

- Some First Nations, Inuit and Métis people feel that "doctors are just treating organs." Health care professionals need to convey that they are treating the whole person and not only the part of their body where the illness is present.
- When the person's illness has not responded to treatment, do not use vague wording to give them this news. Phrases such as "put your ducks in a row" could have an entirely different meaning for First Nations, Inuit and Métis people than what was intended, and such language can be even more confusing when it is translated into Aboriginal languages.
- When a person's death is imminent, families want the doctor to be open and honest in informing them, rather than leaving it up to the community health worker to advise them that their loved one is likely to die in the next few hours.
- First Nations, Inuit and Métis people get frustrated at having to "tell their story to 75 different people" from their diagnosis to the end of life. There is a need for more collaboration between the oncology and palliative care teams working seamlessly. Palliative care is sometimes not offered until the oncology team's job ends. First Nations, Inuit and Métis families would be more comfortable with their loved one receiving palliative care if it had been in place all along.

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.

Guidelines for Working Together







Questions and Decisions

Listening to Wishes

Things to Remember

When someone in a First Nation, Inuit or Métis community is in the advanced stage of cancer or another terminal illness, they could be dealing with a lot of issues and difficult decisions.

For example, they might:

- Have received medical information and terminology that is hard to understand
- Feel distressed and not want to talk about what is happening to them
- Not want to burden or upset family members by getting them involved
- Need to make decisions quickly about whether to do further treatments or not
- Have to decide about their final wishes while they are in pain and feeling upset
- Want to spend their remaining time at home with family, but not want to burden them with their care
- Feel concerned that the community health workers might not be able to provide the necessary pain medications and resources
- Have questions about how traditional medicine will affect their treatment

They might also be worried about what will happen to them in the hospital, hospice or long-term care facility, if care at home is not an option.

They might want to know:

- Whether their family will be accommodated: for example, whether the hospital or hospice will allow many family members and extended family to visit; whether they will be welcomed and not made to feel that they are in the way.
- Whether they will be listened to: for example, if they do not want medical professionals to do everything possible to keep them alive, will this choice be respected?
- Whether their wishes will be respected at the time of death: for example, would the hospital or hospice allow the family to have traditional ceremonies, drumming and singing; after they pass would the family be allowed to spend a few hours saying goodbye to their loved one and bathing their body; would other customs be allowed such as opening a window for their spirit to leave; would other preferences be respected such as not having an autopsy that would disturb the body.

Working Together Effectively:

Caregivers, community health workers, doctors and specialists are all involved with the ill person and family. Caregivers and community workers are often relatives of the ill person.

Given the many concerns the ill person may be facing, it is important for caregivers, community health care workers and health care providers to work together as effectively as possible.

- General practitioners and community health workers should encourage clients to do an advance care plan as a wise practice before they become ill.
- In providing palliative care, just listening and being present is important. Through observing and asking questions, caregivers and community health workers can communicate symptoms to health care providers.
- Family caregivers should be advised that they will need a
 break for themselves. They may not be able to anticipate
 how much work it will be to care for their loved one; they will
 need time for themselves as well.
- Respect the person's privacy. In First Nations, Inuit and Métis
 communities people are often aware when someone is ill.
 The ill person should be able to choose who gets updated
 about their health status, and health care providers should
 ensure they update only those people identified by the ill
 person.
- Health care professionals should acknowledge the 'circle of care' within First Nations, Inuit and Métis communities and offer to include this circle in the person's treatment and discharge planning.
- Make sure the person is aware of and makes choices regarding their care, such as whether they would like to be resuscitated and have other life-saving measures used or not. Ensure that the person's contact people are aware of these choices.
- Accommodate cultural practices and customs such as extended family presence; smudging with sage, sweetgrass or other sacred medicines; drumming and singing; tobacco ties; cedar bath and tea; opening a window for their spirit to travel.