



*Comfort for Those in Need
Caring for the Terminally Ill*

**Aklavik
Inuvialuit**

If you have difficulty reading this document, or have questions, a health provider can assist you.

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Inuvialuit Regional Corporation





Care for the Terminally Ill

Care for the terminally ill means care for sick people whose illness cannot be cured. This care provides comfort and support for ill people and their families.

Health providers offer services to all families dealing with care for the terminally ill. They will work together with you and your family to develop a personalized care program. Your comfort and well-being is very important. Health providers are here to answer to any questions you may have.

Our goal is to ensure that the quality of life of the patient and of the family is maintained as long as possible. This is a very difficult time; we are here to help.

Care for the Terminally Ill

Who is Involved?

You will see a nurse for most of your medical needs. You will also have scheduled appointments with a doctor. A social worker may be involved when there is one available in the community.

Family is very important. Family is always welcome at any appointments you have with a nurse or doctor. If you want to speak with a doctor or nurse alone, that is okay too.

If your family is not able to take care of you at home, hospital care is provided. You will move into a hospital where you have access to 24 hour care.



How Do We Get Started?

A doctor will explore available options with you regarding your illness and care. A meeting will be held with you, your family or friends, a nurse, and a doctor. Sometimes a medical social worker will also be present.

The doctor is at this meeting to explain the details of your illness and diagnosis to you. The nurse is at this meeting to work out a care plan for you and your family.

If you have any questions about your illness, treatment, or any part of your medical care, ask the nurse or the doctor. It is important that you understand what is happening and it is always okay to ask questions and talk about your feelings and worries.



Who is Involved & How Do We Get Started?

Meeting with Health Providers

The following can be discussed when you meet with a doctor or nurse:

- Details of the illness
- Care Options
- Care Plan for you and your family
- Services of the Hospital
- Services of the nurse and doctor
- Option/need of a long-term care facility or hospital
- Supplies that can be provided to your home
- The use of traditional medicines or practices

Throughout your care, health providers will update you and your family on your illness. They are also available to provide your family and/ or caregiver with the necessary training to keep you comfortable at home.

Please ask any questions you may have. We want to work together and support you.

What is a Care Program?

A Care Program is a plan made to work for you, and for the needs of your family when receiving care at home or in the hospital.

While you are making the Care Program with a health provider, do not be afraid to tell him or her what you want. Health providers will do what they can to help you. Express any needs, feelings, concerns, or traditions you have and the nurses will work with you to include them. They will do what they can to find a solution.

When the Care Program is being talked about, this is a good time for you and your family to ask questions. If you do not like a certain aspect of the Care Program, tell your nurse.

You always have the right to say no.



Meeting with Health Providers & What is a Care Program?



What to Expect from Health Providers

- Assessments. The doctor will talk about and explain the illness to you.
- Medical Support
- Emotional Support
- Medication
- Answers to medical questions
- Appointment Times
- Home Care Supplies
- Knowledge
- Assurance
- Medical training for your family

A health provider will work with you to provide the best care possible.

Home Care Equipment

There is equipment for use in the home to make you more comfortable. This equipment is available depending on need and illness.

Home Care Equipment Includes:

- End of Life Care Bed
- Oxygen Concentrator
- Bath Aides
- Wheelchairs
- Walkers
- Commode (portable toilet)

You can discuss your home care equipment needs with a health provider.



What to Expect from Health Providers & Home Care Equipment



Care Options

The following people and places may be involved in your care:

Home Care Nurse - A nurse that will provide nursing care at scheduled times.

Home Care Support Worker – A home care support worker will visit the house at regular, pre-determined times.

The family will be in control in this situation. The nurse will show the family how to give medical care. It is important that family members are involved with this, as it is a lot for one person to deal with alone.

Health Center – The person will have regular appointments at the health center, but will not stay here permanently. The health center contains all available medical resources.

Long Term Care – Long term care may not be appropriate for everyone. Talk with your nurse to see if this is right for you.

If your family member needs this type of care, or if the family is unable to provide care, they will live at and be cared for at a long term facility. Care is available 24 hours at day. Family can visit the patient regularly. The decision to place someone in long term care is made by health professionals and family members.

Hospital – Hospital admission is an option for pain control or respite care. The nurses and doctors and the hospital will work with you so you may go home as soon as possible.

Care Options

Important Discussions

This will not be an easy time, but talking about the following is important.

Discussions to have with family and/or with a social worker:

- Do you have a will telling who you want your possessions to go to after you pass away? Your health provider has information about wills.
- Do you have any final wishes before you pass away? For example, do you wish to go out on the land?
- Do you have any wishes regarding funeral arrangements? (Example: songs, verses, feast, etc.)
- Are your bank documents in order?

Discussions to have with a health provider and with your family:

- Have you appointed someone to take care of you if you can no longer do so yourself?
 - Your Do Not Resuscitate wishes. Do Not Resuscitate or ‘DNR’ is an option that you have. If the time comes when your heart stops or you stop breathing, you have the option not to be put on life support. This decision is very difficult. **Please let your doctor know if you have questions or concerns.** Your health provider has information about “DNR” forms.
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Additional Information

This information may be confusing or overwhelming, but your doctor and home care nurse are available to answer any questions you have. They are here to make your life as comfortable as possible.

- During your care, if you have any traditions or beliefs that you want the nurse and doctor to be aware of, tell them. Your spiritual and emotional needs are just as important as your medical needs.
- You always have the right to say no. If you are not happy with your medication, personalized care plan, or any part of your treatment, let the doctor and nurse know. They will work with you to meet your needs.
- If you are uncomfortable discussing something with your family, talk to the doctor or nurse. They may be able to help you find a way to say what you need to.
- The illness and the medication may make you very sleepy. Do not be afraid to tell people when you need to rest.
- If you have any special wishes or requests, like making a trip out on the land, let your nurse know. He or she may have the resources to help you. A nurse can also supply you with enough medication so you are comfortable while you are away.

Important Discussions & Additional Information

For the Family

It is important to speak up. It is okay to speak for your family member if you think that they are in pain or need something but are not asking for it. Doctors and nurses are here to support both the individual and the family. If you have any questions, please ask.

Some doctors are new to the region. They may need your help to give the patient the best care they can. Tell the health provider what they can do to help you, and if they can they will.

If the person chooses to remain at home for care, this can put strain on the family. It is natural to want to spend all of your time with them, but remember that both you and your family member need rest. It is okay to do something for yourself for an hour; you do not have to feel guilty. If you need to go somewhere, but do not want to leave your family member alone, speak with the health provider. Caregivers can get burnt out very quickly. Remember, you do not need to do this on your own. Health providers can help you.

Grieving

The death of a loved one is very hard to deal with, emotionally and physically. If you need support after a loved one passes on, you can always speak with your doctor or nurse. They will be able to provide you with resources for support.

Decisions will need to be made after your loved one has passed away. If you need information on funeral arrangements, government procedures (banking information, death certificate, pensions, etc.) please speak with a nurse or medical social worker; they may be able to show you where you can receive help.

Resources

HealthLine

Phone: 1-888-255-1010

Aklavik Social Service

Phone: 867-978-2941

Joe Greenland Centre

Phone: 867-978-2381

Fax: 867-977-2237

Aklavik Health Centre

Phone: 867-978-2516

Aklavik Community Counseling

Mental Health and Addictions Counselor: 867-978-2306

Community Wellness Worker: 867-978-2326

National Directory of Hospice Palliative Care Services

<http://www.oulton.com/chpca>

Canadian Cancer Society

1-888-939-3333

Financial Assistance

Contact the Inuvialuit Regional Corporation to determine if financial assistance is available.

Compassionate Care Employment Insurance Benefits

If you have to take time off of work to care for someone who requires terminally ill care, you may be eligible for six weeks of EI benefits. Please visit http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml or call 1-800-206-7218 for more information.

For the Family & Resources