Guide to Cancer Care in Alberta for Newly Diagnosed Indigenous People



General Information



Guiding Prayer

Sacred Father of All Creation

Thank you for the beauty and wonder of life. I pray today for your presence in my heart and mind. I open my heart and mind for your love and guidance as I walk through this time with cancer. I pray for your healing presence within me and I pray for your healing guidance for everyone on the journey with me. May the love and wisdom that heals and creates peace be with me. May the love and wisdom that heals and creates peace be with everyone that is part of my journey. Thank you Creator for the blessings that come this day. Thank you Creator for the blessings in the days that are to come.

Hiy Hiy / Ish Nish / Ĩsniyés / Tsii tsii kii maat Tsii iip / Qujannamiik / Amen.





Words from other travellers

"There is a message that we need to get out there — we don't have a cure for cancer yet, but we have lots of ways to prevent it and we can stop it at the early stages."

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Tell us what you think about this booklet.



What: Online survey

Who: Patients, family and friends

How to access:

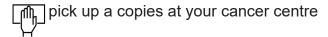
bit.ly/bookletsurvey

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For more information or to view this and other resources:











"I am safer if I do not know I have cancer."

More than half of cancers can be cured, and the long-term effects of cancer can be greatly reduced when the disease is diagnosed early.

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Introduction

Dear Friends,

This booklet has been created for Indigenous cancer patients and their families.

Cancer can create stress and worries about the future. The information in this booklet might help answer some of your questions and concerns.

You'll also find information about supports and services provided at the Cancer Centres and the Indigenous Health Program for Indigenous people.

Words from other travellers

"Cancer doesn't behave the same in every person. If someone has passed away, that doesn't mean that the next person will pass."

Cancer and Cancer Treatment

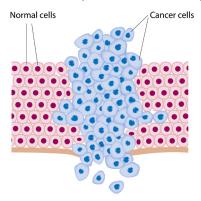
What is cancer?

Our body is made up of many cells. **Healthy cells** follow the "rules" of when to divide and die.

Healthy cells dividing:



Cancer happens when the cells start to grow out of control. When these cells grow and divide, they can form a lump called a **tumour**. Not all tumours are cancer. Some are non-cancerous (also called **benign**).



It is very important to find cancer in the early stages, because it is easier to treat and there's less chance of it spreading.

Words from other travellers

"I survived cancer because I went for all recommended cancer screening tests. I can still enjoy time with my grandkids. I will continue to live a healthy life and be able to do all the things in life I hoped to do."

Cancer treatment

Learning about the different treatments available can help you understand the medical visits you need to do and help you make decisions about your treatment.

If you are planning or receiving care from a traditional healer, Indigenous Health Program staff can help you speak with your health care team at the cancer centre.

Types of treatment include:

Surgery

Most surgeries happen in operating rooms and an overnight stay may be needed so you can be monitored. Smaller surgeries, called "day surgeries", do not need an overnight stay.

Systemic Treatment

Systemic treatment includes drugs such as chemotherapy, targeted therapy, immunotherapy or hormone treatment. These drugs target and destroy your cancer cells. You may get these drugs through an IV (intravenous), by injection or by taking pills orally.



Radiation Treatment

Radiation treatment is a cancer treatment that:

- Uses radiation to kill cancer cells and shrink tumours
- Treats many types of cancer and some conditions that are not cancerous
- Can be used alone or with other treatments such as surgery, chemotherapy, targeted therapy, immunotherapy, or hormone treatment

Types of radiation treatment:

- External Beam the radiation is produced by a machine and aimed at the tumour, so the radiation source comes from outside of the body.
- Internal Radiation the radioactive source is placed inside the body, either inside the tumour, or close to it. This is called brachytherapy.

No Treatment

Sometimes no treatment is an option. This is called "watch and wait" and depends on how fast the cancer is growing and what type of cancer you have. You also have the right to consider not having the usual medical treatment

Traditional Healing

Within Indigenous cultures, there are many types of healing that have been used with medical cancer treatment successfully. They are often linked to the medicines of the land and can include ceremony, spiritual, and psychological approaches to healing.

Contact a Cultural Helper or a respected Elder from your community to help connect you with a traditional healer.

Words from other travellers

"My aunt was diagnosed with cancer, and we felt we were only going to have her for 6 months. We had her for 10 years. She took a very holistic approach towards the cancer. She did radiation and chemotherapy and traditional medicine. Then she participated in research that extended her life. She lived it to the best of her ability with a positive attitude. That made a big difference."

Oncologists (cancer doctors)

Oncologists are doctors with special training who treat people with cancer.

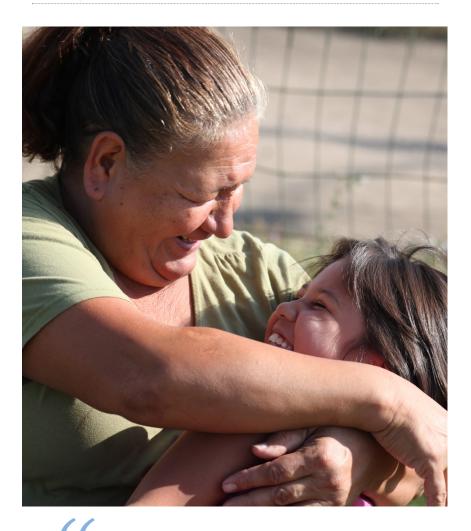
The main types of Oncologists include:

- Medical Oncologists use medicines such as chemotherapy.
- **Surgical Oncologists** use an operation to remove tumours and nearby tissue.
- Radiation Oncologists use radiation treatment.

Other types of Oncologists:

- · Pediatric Oncologists treat cancers in children.
- Hematologists treat cancers found in the blood, such as leukemia, lymphoma, and myeloma.
- Gynecologic Oncologists treat cancers found in females, such as uterine or cervical cancer.





COMMON MYTH

"I am afraid my cancer will spread to my children."

Cancer cannot be spread to others with everyday contact or activities, such as hugging or playing.

Preparing to Enter Cancer Care

Learning about a cancer diagnosis can cause a great deal of anxiety as you worry about your future and family. You may be afraid to learn more about your diagnosis, or have concerns about finances, childcare, or how your family will take the news.

Information about what to expect when you arrive at the Cancer Centre can help you and your family prepare as much as possible.

Before your first visit

- Think about what is important to you.
- Make a list of questions for the health care providers

 what to expect, different treatment options,
 nutrition, exercise, traditional supports and family visits.
- Be prepared to stay near the cancer centre if you are travelling far from home.
- Contact the Cancer Patient Navigator or Resource Social Worker if you need help with travel arrangements (see page 23).
- Speak with your community health centre about support services.
- Speak to an Elder or traditional healer if you are looking for traditional supports.

Words from other travellers

"A friend of mine would just stop by for 10 minutes and ask, 'How are you feeling? How are you doing?' It wasn't everyday. Maybe once a week. It was just nice to have someone pop by and say, 'Hey! How are you doing? Do you need anything?'



"Cancer is a disease that has to run in your family."

Specific genes, such as those found in some breast cancers, may be passed from one generation to the next, so it is important to see your health care provider if you are concerned about your family history.



Walking with family

Bring a family member or friend to your medical appointments. This will be a huge support for you both.

Think about the kind of support you need from your family member or friend.



Companion Characteristics:

Someone:

- · You trust.
- · Who is healthy.
- · Who keeps their appointments.
- You can speak to about your fears, concerns and questions.
- Who will be honest about what health care providers say if they are helping to translate.

Companion Skills:

- Speaks and understands English well
- Speaks your Indigenous language and understands your beliefs on culture and spirituality
- Can help ask the health care providers questions
- Can support you in making decisions about your treatment
- Can report back to family the information that was shared at your appointments
- Can advocate for you and your needs



When faced with cancer, it is common to worry about your future and family. You can use these tips or create your own to help you cope.

Tell yourself "I will":

- Increase my knowledge of wellness.
- Focus on the facts not my fears.
- Share my diagnosis with someone I trust.

Words from other travellers

"It's just another sickness. I'm not giving up. A lot has to do with how you deal with it, how you think. Your mind has a lot of power. Your brain has a lot of power."



Sharing your cancer diagnosis

One of the biggest challenges is sharing the news with family and friends. You may feel scared, uncertain and in shock.



The word cancer brings out different feelings in each person. It is important to know that each person may need a different amount of time to accept the diagnosis.

Sometimes, the person with the cancer diagnosis may think it best to keep the information from their loved ones to keep them from feeling pain and worry. But eventually family and friends will realize that something is wrong.

Words from other travellers

"When the spirit is strong, life is good."

Tips for sharing a cancer diagnosis:

Remember to be as honest as possible about the situation and about your feelings. You do not need to look happy or brave if that is not how you feel.

Prepare for the conversation

Think about sharing at a time when you are ready.

Gather information and get a better understanding of what the diagnosis means to you.

Create the right environment

Share the news in a calm and private place so family members can express their feelings and emotions.

Get rid of distractions such as the TV, computer or cell phones.

Have someone nearby to support you when you share the diagnosis, like a friend who already knows.

Words from other travellers

"As a family, we were awakened to the power of Indigenous medicine and ceremony. Our family went through a process of learning the beauty of our own healing methods. We became stronger as a result."

Start the conversation

Use "I" statements.

- "I think it would be good to tell you what is happening to me. Is that okay?"
- "I have something serious to talk to you about."

Clarify questions and concerns for loved ones who already know a little bit about the situation.

 "I think you might know something is wrong. Can you tell me what you know so I can answer your questions?"

Give information in small amounts and check to make sure people understand.

- "Does this make sense to you?"
- "Do you see what I mean?"

Understand that some people will react differently to the news

Hold hands or sit together quietly until people feel comfortable to talk or ask questions.

Try asking a simple question.

- "What are you thinking about?"
- "Can I share something with you?"

Take control of the things you can

- Rest when you are tired.
- Plan your days and do the things you have the strength to do.
- · Eat healthy meals.
- Live a healthy lifestyle avoid alcohol and drugs.
- · Let family and friends share your responsibilities.
- Keep a journal with all your appointments and information.
- Speak to a traditional healer or Elder about spiritual and traditional supports.





Practice cultural activities

- Visit with Cultural Advisors and Helpers.
- Ask the Cancer Patient Navigator if there is cultural support available.
- Use your traditional language to talk about the disease with others who understand.
- Learn about living life in a healthy way.
- Learn about protocols and cultural support from Cultural Advisors and Elders for things like hair loss, thanking the Creator, saying goodbye to loved ones or letting go of physical life.

Words from other travellers

"Even though I could have put together a list of 10 things that I needed, I would just say, "Thank you. I needed that."

Remind yourself, "I am not alone"

- Talk about your feelings.
- Be open to support from family and friends, co-workers, support programs and health care providers.
- Find good ways to talk about your feelings your hurt, sadness, anger, guilt, denial, fears, or painful thoughts.
- · Walk toward family and friends, not away.
- Share your thoughts and feelings about the good things that happen.
- Share your thoughts and feelings to help family and friends understand.
- · Call someone you trust when you are feeling down.



Get to know who can help

- Talk to people who can help you and tell them what is happening.
- Do not be afraid to say what you feel is important about you and your care.

- Talk to your Elders or Cultural Advisors about traditional forms of support.
- Look for spiritual support such as Pastors, Ministers, Indigenous Health Program staff and Elders in your home community or through Cultural Advisors or Spiritual Care Specialist at a Cancer Centre or in a hospital.

Words from other travellers

"My community did auctions and a bingo because I had to quit work for a year. I got a lot of support to help pay for driving, the gas, meals and to pay my bills. My community helped a lot."



Nutrition

Eating the right kinds of foods before, during and after cancer treatment can help you feel better and stay stronger. Cancer and cancer treatments may affect your taste, smell, appetite and your ability to eat enough food.

Some key points about nutrition and cancer include:

- Healthy eating habits and good nutrition can help you deal with the effects of cancer and its treatments.
- Loss of appetite and severe loss of muscle are common causes of malnutrition in cancer patients.
- It is important to address weight loss caused by cancer and its treatments.
- People who are well nourished have a better chance of recovery and quality of life.

A healthy diet includes eating and drinking foods and liquids that include:

vitamins

carbohydrates

minerals

fat

protein

water

This includes traditional foods like wild game, fish, bannock, and soups made with the bones of animals.



There are many more resources, such as videos and information booklets, that are available to learn about cancer and nutrition. You can ask for help from a dietitian at a Cancer Centre or from your local Health Centre.

Exercise

Staying active is important for returning to good health. It may help decrease fatigue that often happens with cancer and its treatments. Regular exercise may also help you with sleeping problems, depression, anxiety and keeping a healthy weight.

Ask to speak to a Rehabilitation Specialist, who can help you learn more about proper exercise, staying active or increasing how much exercise you get each day.

Always check with your doctor before beginning or changing your exercise program and increasing your level of physical activity.



COMMON MYTH

"You can only get cancer if you don't eat right, don't exercise or smoke cigarettes and drink alcohol."

Avoiding the use of tobacco or the intake of alcohol and street drugs and eating healthy foods along with being physically active can greatly reduce your chances of experiencing a cancer illness, but even people who live a healthy lifestyle can develop cancer sometimes.

Using tobacco

We know it can be difficult to quit or reduce smoking or chewing tobacco and often takes several tries. But even after a cancer diagnosis, you can improve your health and body's response to treatment by quitting.

Studies show many important benefits of quitting or reducing the use of tobacco after a cancer diagnosis:

- A better chance of successful treatment
- Fewer serious side effects
- Faster recovery from treatment
- Decreased risk of the cancer coming back, or getting another cancer diagnosis
- Lower risk of infection
- Easier breathing
- · More energy and a better quality of life

Cancer patients who quit tobacco say they **feel better physically**, **emotionally**, and **have a better quality of life!** Now is the BEST time to be tobacco free.



Alberta Quits:



www.AlbertaQuits.ca



1-866-710-QUIT (7848)

Spirituality

Spirituality can provide an important source of support and protection for many Indigenous people during a cancer experience. Whether your practices include going to church services or getting counselling from a community Elder, these kinds of supports are available at a cancer centre and through the Indigenous Health Program.

Healing and connecting

Renewing and making connections with family, community and the land can help you heal yourself spiritually, mentally and emotionally. Share your memories and thoughts about your life with others or participate in traditional activities out on the land, such as gathering foods, cooking by a fire or attending ceremonies



Preparing the spirit

When a cure is not possible, speak to a traditional healer or Elder for emotional and spiritual support. Traditional beliefs in many Indigenous cultures see death as a time of 'transition' that needs preparation. A focus during this time is often on the 'heart' and the 'spirit'. The heart is the pathway for the spirit to be connected to life, and we feel our way back to the spirit world.

Although beliefs about where the spirit might go next may be different, most agree that death is not an 'end' but a normal part of the 'circle of life'.

Other forms of help include palliative care. Palliative care helps improve quality of life for people diagnosed with an advanced illness. This kind of care is about managing symptoms, providing information and making decisions with you and your family. It is about respecting your wishes and making sure you receive the emotional and spiritual support you and your family need.



"If I visit a person who has cancer, I might get cancer."

Cancer is not contagious and cannot be passed from one person to another through everyday contact or normal activity. However, human papilloma virus (HPV) is a sexually transmitted infection that can lead to the development of some cancers. If you want to learn more about HPV, speak with your health care provider.

Services and Programs

Home and community care

Health Canada works with Indigenous communities to develop home and community care services that respect traditional, and holistic ways to healing and wellness.

These services help people with illnesses get the care they need in their home or community so people can be as independent as possible and close to their loved ones.

Home and community care may include:

- · Nursing care
- · Personal care such as bathing
- Home support such as meal preparation
- In-home respite care to give family members a rest

Contact your local Health Centre for support and services.

Psychosocial and family counselling

Supports for mental health and psychosocial services have shown to reduce stress and help improve quality of life. Cancer centres provide many services to help patients and families cope. Your health care providers can give you more information about these services.



Cancer Patient Navigation

Cancer Patient Navigators are registered nurses with training in cancer care and navigation. They:

- Work at the community and regional cancer centres
- Guide patients through cancer tests, appointments, treatments and emotions
- Offer support close to home
- Help patients and families before, during and after treatment

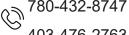
Ask your doctor or clinic nurse at your next visit how you can get in touch with a Cancer Patient Navigator.

Indigenous Cancer Patient Navigators

Are Cancer Patient Navigators who provide additional support to Indigenous patients and families throughout the province. They:

- Find cultural peoples to help facilitate cultural practices
- Interpret medical terms
- Advocate for patients, and help answer questions about diagnosis and treatment
- Help health professionals to better understand Indigenous peoples, and their cultural ways
- Connect clients to services and resources

To get in touch with an Indigenous Navigator call:



780-432-8747 (Edmonton and North)

403-476-2763 (Calgary and South)

Indigenous Health Program

- Improves care for Indigenous people by working with the health zones to help develop and deliver health services.
- Uses cultural and spiritual supports for Indigenous people to help deliver culturally safe health services. The service does not provide access to traditional medicines or ceremonial practices.





ttp://www.albertahealthservices.ca/aboriginal.asp



Calgary 403-943-0195 Edmonton 780-735-5326

Cultural Helpers

Cultural Helpers can provide:

- Cultural and spiritual support to Indigenous patients and families to help them through difficult times and to ease the cancer experience
- Cultural awareness and support for cancer centre staff to help create a better understanding between cultures
- Counselling can talk with you about your fears, hopes, future plans, to relieve stress, and to provide encouragement.
- Loss and grief available to support Indigenous patients and families throughout a cancer illness.

First Nations and Inuit Hope for Wellness Help Line

Health Canada has a 24-hour toll-free Mental Wellness Help Line for Indigenous people and provides counselling in English, French and, upon request, Cree, Ojibway, and Inuktitut.



(1-855-242-3310



Words from other travellers

"A cancer diagnosis does not automatically mean you will die. If cancer is found early, we can survive and go on to have a good life."

Know Your Rights

Knowing your rights as a patient can help you and your family get the resources and support you need.

Patients' rights

"You're given the choice to say yes or no. You are the only person who knows your body. All of our teachings say that your gift in life is choice."

Declaration on the rights of Indigenous people

This document states that it is important for Indigenous people to have the same health rights and health status as other Canadians.

Indigenous people have the right to:

- their traditional medicines and health practices, such as using medicinal plants, animals and minerals.
- access, without any discrimination, to all social and health services.
- the enjoyment of the highest standard possible of physical and mental health.



Within the health care system you have the right to:



- be treated with care, dignity and respect
- privacy about your cancer diagnosis, treatment and results
- review your health records
- receive and understand information from your health care provider about your diagnosis, treatment options, and other information

Your rights related to your treatment for cancer include the right to:

- receive and understand information about the benefits and risks of a procedure or treatment
- decide to receive treatment or not
- refuse to sign a consent form (agreement) if you do not understand what you are being asked to sign
- change your mind about any treatment even if you have signed a consent form
- · be as pain free as possible
- speak about your concerns of the care and services you receive without fear that it may affect your care



Your rights related to traditional healing and medicines include the right to:

- practice your spiritual beliefs including ceremony and prayer alongside receiving medical cancer treatment
- use traditional forms of treatment including traditional medicines or other forms of care



Other Resources

Canadian Cancer Society

The Cancer Connection program offers support to cancer patients and their caregivers from people who have experienced a cancer illness or cared for a person with a cancer illness. You can talk with caregivers or current and former patients with your same type of cancer.



1-888-939-3333



www.cancerconnection.ca



"Screening tests are painful."

In general, screening for cancer causes little or no physical discomfort, and regular screening can prevent and may greatly increase chances for a cure from cancer if the disease is caught early.

Canadian Virtual Hospice

This website provides support for palliative and end-of-life care, loss and grief, as well as tips for Talking With Your Health Care Providers.



www.virtualhospice.ca

Cancer Chat Canada

This website offers support groups led by health care providers for people affected by cancer.



www.cancerchatcanada.ca

Cancer View Canada

This website provides information about cancer, including specific resources for Indigenous people.



www.cancerview.ca

Living My Culture

Indigenous Voices Stories of Serious Illness and Grief was developed by Indigenous people for Indigenous people (video series).



www.LivingMyCulture.ca

Indigenous Cancer Care Experiences

Funded by the Canadian Partnership Against Cancer, the Dialogue and Storywork project aims to improve Indigenous cancer patient experiences using videos to increase knowledge and information for primary and oncology care providers of Indigenous cancer patients, their families and communities.



myhealth.alberta.ca/alberta/indigenous-cancer-care

Partners on the project:

- Canadian Partnership Against Cancer
- CancerControl Alberta (AHS)
- Government of the Northwest Territories (GNWT)
- CancerCare Manitoba (CCMB)
- BC Cancer Agency (BBCA)
- Saint Elizabeth Health Care (SEHC)

Most of the information in this document has been gathered by:

- Working with Indigenous people in Alberta.
- Using work that has been done in close consultation with Indigenous people across Canada.



All of the information has been reviewed by Indigenous people who are considered experts working in the field of Indigenous health.

AHS CancerControl Alberta wishes to give special thanks to the following for their support in creating this booklet:

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- Indigenous
 Communities in Alberta

Common Terms		
Benign	Not cancer and will not spread to other parts of the body	
Cancer	Abnormal cells that can grow out of control and can spread to other parts of the body	
CAT Scan (Computerized Axial Tomography)	An imaging test or picture of inside the body used to diagnose cancer and other illness	
Cervical Cytology Screening	Known as the Pap Test; used to detect abnormal changes in cells of the cervix	
Malignant	A tumour that is cancerous and may spread to nearby healthy tissue or other parts of the body	
Mammogram	An x-ray that checks for changes in breast tissue to screen for breast cancer	
Metastasis	Spread of cancer cells from one part of the body to another	
OBT (FIT Test)	Test for blood in feces or stool that may detect early signs of colon cancer	
Palliative Care	Treatment and care of people with advanced illness — provide information, help manage symptoms, plan end of life care	
Prognosis	The outlook or chance of recovery from the cancer	
PSA (prostate- specific antigen)	Blood test that measures the level of PSA in men used to screen for cancer	
Radiation Treatment	High energy x-rays used to destroy cancer cells	
Systemic Treatment	Treatment of cancer with special drugs or a combination of drugs	

