

Guide to Cancer Care in Alberta for Newly Diagnosed Indigenous People

General Information




Cancer Care
Alberta

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 / Īsniyés / Tsii tsii kii maat Tsii iip /
Qujannamiik / Amen.



**“Thank you Creator
for the blessings that
come this day.”**



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For more information or to see this and other resources:



www.ahs.ca/cancerindigenous



pick up a copy at your cancer centre





COMMON MYTH

"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.

Introduction

Dear Friends,

This booklet has been created for Indigenous people facing cancer themselves or with a family member.

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..

Words from other travellers

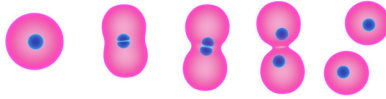
"Cancer doesn't behave the same in every person. If someone has passed away, that doesn't mean that the next person will pass."

Cancer and Cancer Treatment

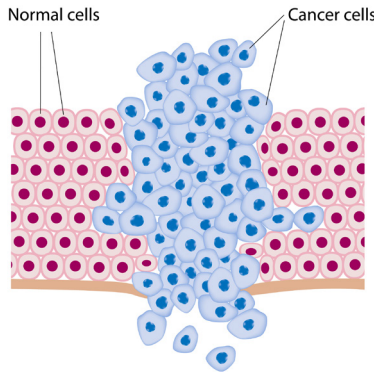
What is cancer?

Our body is made up of many cells. **Healthy cells** know 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.

You can choose whether to take medical treatments, traditional healing, or both. If you are planning or receiving care from a Traditional Healer and want help talking with your cancer care team, an Indigenous Cancer Patient Navigator or Cultural Liaison can help you.

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.”

Types of treatment include:

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



Surgery - involves cutting out the cancer and some of the healthy tissue around the cancer. 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.

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 - 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 you connect with a Traditional Healer.

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 such as uterine, ovarian, 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

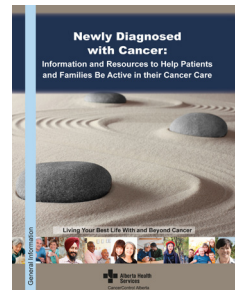
- Think about what is important to you.
- Make a list of questions for your healthcare providers — what to expect, different treatment options, nutrition, exercise, traditional supports and family visits.
- Be prepared to stay near the cancer centre if you are travelling far from home.
- Contact the 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.

Find more information, tips and supports in **Newly Diagnosed with Cancer** - a book for patients and families.



www.ahs.ca/cancerdiagnosed

> Newly Diagnosed



COMMON MYTH

“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 healthcare 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 healthcare providers say if they are helping to translate.

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?’”

Companion Skills:

- Speaks and understands English well
- Speaks your Indigenous language and understands your beliefs on culture and spirituality
- Can help ask the healthcare 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

Cancer centres in Alberta

Alberta has 17 cancer centres. Supports are available no matter where you get your cancer care. Find out about the cancer centre you are going to.



www.ahs.ca/cancerdiagnosed

> Cancer Centre Information

What You Can Do to Help Yourself

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.

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

"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."

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 healthcare 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.



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.”

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 Elders, Pastors, or Ministers in your home community or through a Cultural Liaison or Spiritual Care Provider at a cancer centre or in a hospital.



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
- fat
- minerals
- 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.

Keeping tobacco sacred

Traditional tobacco is a sacred plant and a gift given by the Creator to Indigenous people. It's important to honour the role tobacco plays in many Indigenous cultures.

Commercial tobacco is different. Chemicals have been added to make it more addictive and more harmful. Over time, commercial tobacco has become a dangerous drug of abuse.

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 commercial 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 using commercial tobacco say they **feel better physically, emotionally, and have a better quality of life!**



Alberta Quits:



<https://albertaquits.healthiertogether.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. There are many ways to care for your Spirit:

- Traditional prayer and ceremony
- Other spiritual or religious practices
- Honouring your whole self with good foods and physical activity
- Spending time connecting with family, friends and the land



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.

Words from other travellers

“When the spirit is strong, life is good.”

Preparing the spirit

When a cure is not possible, speak to a Traditional Healer, Knowledge Keeper, 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.

COMMON MYTH

“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 healthcare provider.

Services and Programs

Home and community care

First Nations communities have home and community care services that respect traditional, and holistic ways to healing and wellness. Contact your community Health Centre for support and services.

There are also home care services throughout Alberta that can be accessed by First Nations, Métis and Inuit people. Call 811 to find home care services near you.

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

Psychosocial and family counselling

Supports for mental and emotional 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. Ask your care team for more information or look online.



www.ahs.ca/cancersupportivecare

> Psychosocial Oncology

Cancer Patient Navigators

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 how you can get in touch with a Cancer Patient Navigator.

Indigenous Cancer Patient Navigators

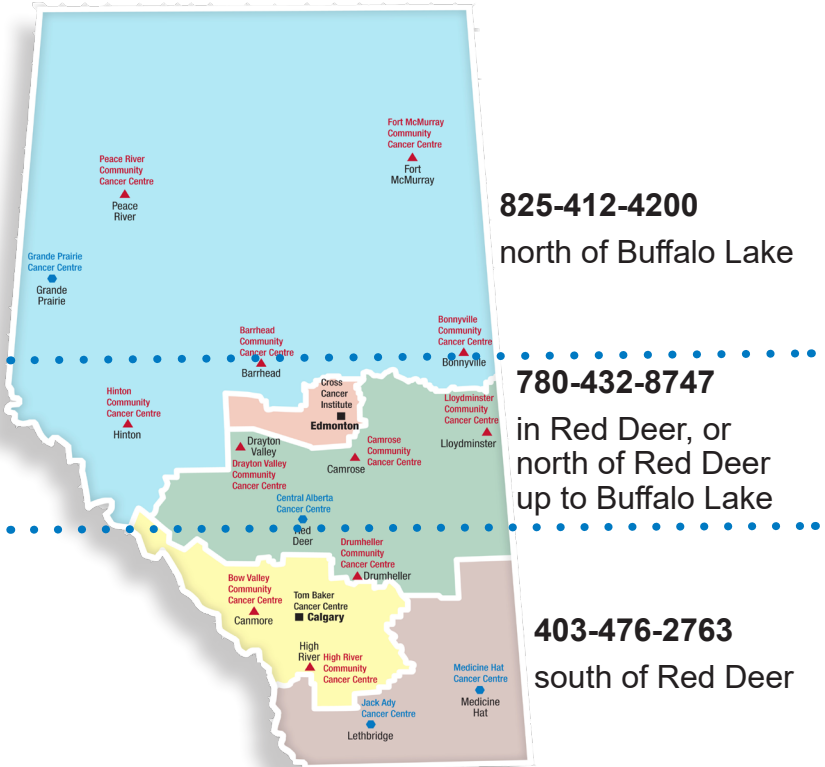
Indigenous Cancer Patient Navigators provide additional support to First Nations, Métis and Inuit patients and families impacted by cancer. They can help wherever you are in your cancer journey with:

- Navigating the healthcare system and answering questions
- Providing support and information
- Connecting you to emotional, spiritual, mental and physical support from a cultural support worker or Elder, counsellor, physiotherapist, or others to support your wellbeing
- Advocating for you to help get your questions answered and your concerns addressed

Services are free and confidential.



To connect with an Indigenous Cancer Patient Navigator call the number connected to the area where you live or are getting cancer treatments, or ask for a referral.



If you're not sure what number to call, pick a number above and the navigator will connect you to the person who can best support you



Indigenous Wellness Core

- 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.



www.ahs.ca/indigenous

Indigenous/Cultural Wellness Coordinators

Wellness Coordinators are available at many hospitals. They can provide:

- Cultural and spiritual support to First Nations, Métis and Inuit patients and families to help them through difficult times and ease the hospital experience. Ask about help accessing traditional wellness or ceremonial supports.
- Cultural awareness and support for cancer centre staff to help create a better understanding between cultures.
- Information, help navigating the health system, and connections to other health services and supports.




Ask about the supports and services where you are getting your care.



Hope for Wellness Help Line

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

 1-855-242-3310

Indigenous Cancer Sharing Circle

Join Indigenous patients and caregivers living with cancer across Alberta by phone or online. The sharing circle is hosted by Wellspring Alberta and co-led by an Elder. You can join this session online or by phone. All Nations are welcome to join, connect and share in a safe space.

 1-866-682-3135

 <https://bit.ly/IndigenousCancerSharingCircle>

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.”

Métis Nation of Alberta (MNA) Supports

The MNA has supports and services available for Métis Albertans including:

- Compassionate Care: Cancer Transportation Program for people 18 years of age or older
- Support to Medically Necessary Accommodations
- Help finding resources



1-780-455-2200 Ext. 115



<https://bit.ly/mnawellness>

> Cancer Resources & Programs

Non-Insured Health Benefits (NIHB)

NIHB can provide coverage for some health-related costs that are not already covered by the health system or other programs. This coverage is provided by Indigenous Services Canada and is available for eligible First Nations and Inuit people.

NIHB, including local community Medical Transportation, can help with long distance travel arrangements. The benefits may also help with supports you need for mobility, changes to your body or medications not paid for by Alberta Health.

Ask your care team for more information or help accessing NIHB.



<https://bit.ly/noninsuredhealthbenefits>

Know Your Rights

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

Patients' rights

Words from other travellers

"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 healthcare 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 healthcare provider about your diagnosis, treatment options, and other information

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

- ask questions and get information to help you understand the benefits and risks of a procedure or treatment
- refuse to sign a consent form (agreement) if you do not understand what you are being asked to sign,
- decide to have treatment or not
- 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

Your cancer care is important to us. If at any time your rights are not respected or you have a very good experience you want to share please:

Ask to speak with a manager at the cancer centre where you get your care

Talk with an Indigenous Cancer Patient Navigator or Wellness Coordinator about your experience and get help sharing it

Call the AHS Patient Relations team toll free at 1-855-871-4340 or find them online:

<https://www.albertahealthservices.ca/about/patientfeedback.aspx>

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

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 Healthcare Providers.



www.virtualhospice.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 Dialogue and Storywork project:

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



Common Terms

| | |
|---|--|
| Benign | Not cancer and will not spread to other parts of the body |
| Cancer | Abnormal cells that 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 find cancer and other illness |
| Cervical 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 | An added layer of support for patients and families at any stage of cancer care — 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 PSA levels; used to screen for prostate cancer |
| Radiation Treatment | High energy x-rays used to destroy cancer cells |
| Systemic Treatment | Treatment of cancer with special medicines or a combination of medicines |



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.

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Alberta Cancer
FOUNDATION

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The information is to be updated every 3 years, or as new clinical evidence emerges. If there are any concerns or updates with this information, please email cancerpatienteducation@ahs.ca.

Cancer Care Alberta

Leading care through compassion, courage, learning and discovery

