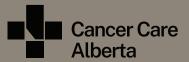
Newly Diagnosed with Cancer:

Information and Resources to Help Patients and Families Be Active in their Cancer Care



General Information



Being diagnosed with cancer can be life-changing.

We want you to know that you are not alone.

Cancer Care Alberta (CCA) is here to help. We are part of Alberta Health Services and provide care at 17 cancer centres across the province.

Working with many partners, CCA is like a compass—setting the direction for cancer care in our province while supporting patients and families climbing their own personal mountains.

Help and support is available — whether it is with someone from your care team, a friend or family member or the contacts and resources listed in this book.

This book will give you information about what to expect, how to get support, resources you can use, and things you can do as you move forward.

We are here for you.

This book is about helping you, as you manage cancer and cancer care. Since everyone is unique, not everything will be important to you. Begin exploring the Table of Contents or Overview of Options. You will find the rest of the book divided into 3 sections:

- Manage Your Cancer Care
- Manage Your Wellbeing
- Use Helpful Tools to Take Action

Use the book as you wish - skip to a section that interests you, read smaller sections or even the whole book. Use it like a workbook. Try adding your own notes, highlighting important sections or checking off tasks you have finished.

This information is meant to help you as you have conversations with your care team, family and friends. There are also things you can do to help you in your cancer care, one day at a time. Find a copy online to share with family and friends, or use it to access clickable links: www.cancercarealberta.ca > Patients and Families > Just Diagnosed

Using this book:

- Take it one step at a time and ask for help when you need it.
- Helpful symbols to know:



this or these – suggest actions you may want to try





Web – shows a web page link to an online resource

» \bigcirc Arrow with magnifying glass – shows a keyword or phrase to use when searching a website

For classes, groups and events, visit: www.ahs.ca/cancerclasses



Manage Your Cancer Care

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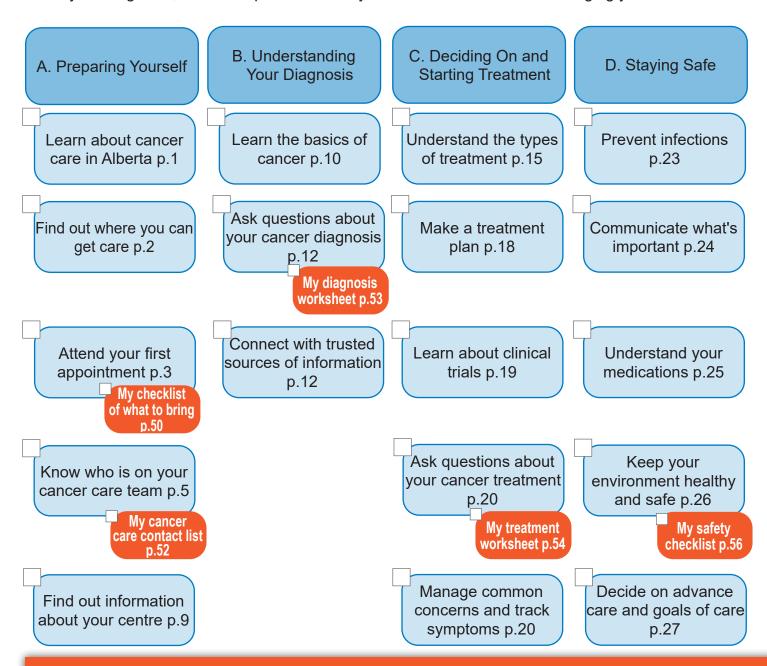
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Overview of Options



Manage Your Cancer Care

There are many things to know and do when managing your cancer care like arranging transportation, attending appointments or managing any side effects. It can help to have information about your diagnosis, what to expect and what you can do to be active in managing your cancer care.



Use Helpful Tools to Take Action

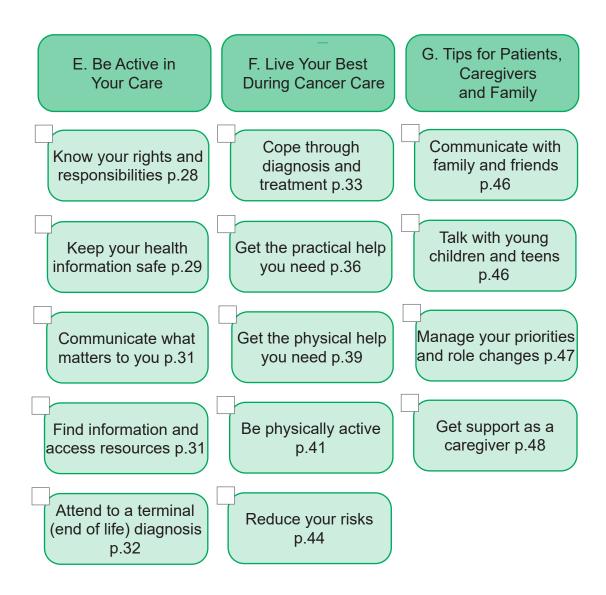
Every person finds their own way of coping with a cancer diagnosis and treatment. Sometimes it takes time to find your way. Other people might offer you advice. What works for one person, doesn't always work for another, and that's okay. Focus on what you need, as you need it. This orange section of the book is action-focused — it has worksheets and checklists you can use.

Overview of Options



Manage Your Well-Being

You may have good and bad days, but managing your well-being is something you can do one day at a time. Your physical, mental, emotional, spiritual and social well-being are all related and affect one another. Taking action to maintain or improve even one of these areas may have positive effects on other areas. For example, moving your body regularly can help you feel less tired.



The **blue** and **green** bubbles in the overview above are topics you may wish to know more about.

The **orange** bubbles let you know about worksheets you can use. These are at the end of the book so all of your information is kept in one place.



Manage Your Cancer Care

This section includes information on who you will see for appointments, what to expect and how to manage common concerns.





Preparing Yourself

A1. Learn about cancer care in Alberta

Cancer Care Services Start After a Cancer Diagnosis*

Before you come to the cancer centre, the doctor who referred you should complete all of the needed tests and blood work. If this hasn't happened, a triage nurse (sometimes called triage coordinator or a nurse navigator) will contact the doctor and ask them to do this. Our triage nurses are registered nurses who coordinate referrals to the cancer centres. They work to book patients with the right doctor. They also support patients by explaining treatments and tests and help you prepare for your consult visit.

Once a diagnosis of cancer is confirmed and a referral is made to Cancer Care Alberta (CCA):

- Your first appointment will be arranged.
- You will get an appointment letter in the mail and the triage nurse may contact you with details for your first appointment.
- Our registration team members may contact you to check your personal and insurance information before your first appointment.
 - *Sometimes, patients will come to a cancer centre to see an oncologist or other specialist, when they have a pre-cancer diagnosis. If this is you, the materials, resources, classes and supports are available for you also.

Our Cancer Centres

CCA is part of Alberta Health Services and is responsible for the programs and services at 17 cancer centres in the province. The centres offer different levels of service and are grouped into 3 different levels or "types" of centres.

Tertiary Centres	Large cancer centres that offer a full range of specialist services.	 Cross Cancer Institute (Edmonton) Arthur Child (Calgary)	
Regional Centres	Medium-sized centres that offer many, but not all specialist services. These centres provide systemic treatments and some provide radiation treatments.	 Radiation and Systemic Treatment Central Alberta Cancer Centre (Red Deer) Jack Ady Cancer Centre (Lethbridge) Grande Prairie Cancer Centre (Grande Prairie) Systemic Treatment only Margery E Yuill Cancer Centre (Medicine Hat) 	

Community Centres	
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Smaller centres in the local hospitals. They offer some systemic treatment and symptom management services.

- Barrhead
- Bonnyville
- Bow Valley (Canmore)
- Camrose
- Drayton Valley

- Drumheller
- Fort McMurray
- High River
- Hinton
- Lloydminster
- Peace River



A2. Find out where you can get care

This map shows you where the 17 cancer centres are. Ask where your appointments will be and what treatments are available there.

Check out 'Getting the practical help you need' (see page 36) if travel or financial issues are a challenge for you.

Care Closer to Home

We try to keep you as close to home as possible. But sometimes, people need to travel to a cancer centre that offers the type of treatment they need. Talk to your doctor or clinic nurse about care closer to home. You may be able to receive some or all treatments and supportive services closer to where you live. Some examples:

- some patients start their systemic treatment in a Tertiary or Regional centre and complete it at a cancer centre closer to home
- people living in south Calgary can sometimes have their treatments in High River

When You Live Outside of Alberta

If you live in another province and are going to a Cancer Care Alberta centre, there are other steps needed. For example, your home province may need to pre-approve your treatment in Alberta. We may need to wait to book your treatment visit until we receive this approval.



A3. Attend your first appointment

Getting to the Centre

Public Transportation

Depending on what centre you are going to, public transportation may be available. Contact Alberta 211 to find out what options are available for you.

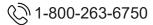


To plan your route to the tertiary centre or for more information:



Canadian Cancer Society Wheels of Hope Program

The Canadian Cancer Society has volunteers who donate their time and vehicles to drive patients to and from their active cancer treatment appointments in some cities. There is a yearly registration fee of \$100 for this service.



Parking

Information can be found at: www.albertahealthservices.ca/Parking/



Ask at your centre if weekly or monthly parking passes are available.

Time

Arrive early for your appointment to give yourself time to park and make your way to the reception desk at the main entrance to check in.

How long will my first appointment take?

You should plan to spend 2 to 4 hours for your first visit. Future visits may be shorter, but it's a good idea to always allow yourself extra time.

Help with Mobility

Wheelchairs should be available at the main entrances of the centres.

Identification

When you arrive at the main reception, check in with the clerks at the desk. You will be asked to show one piece of photo ID (identification) and a second piece of government ID. We suggest your healthcare card along with your driver's license or your Status/Treaty card.



What to Bring to Your Appointments

Being prepared for your appointment can help make the experience smoother and more comfortable. Review and complete the checklist on page 50 to make sure you have everything you need.



Remembering Information

At your first appointment you will get lots of information about your diagnosis and treatment. It can be overwhelming and hard to remember everything. It can be helpful to:

- Have someone come with you to listen and take notes. There is space for one or two people you trust to attend your appointments with you.
- Take notes during the conversation. You might want to have a notebook that
 you use for all of your appointments or write in the books you are given like
 this one.
- Use the free AHS My Care Conversations app so you can audio record your conversation with your healthcare team. Find out how where to download and how to use the app on page 30.

Pregnancy and Fertility

Pregnancy

Treatments to someone who is pregnant can affect the unborn baby. Tell your doctor right away if you think you may be pregnant or if you have been trying to get pregnant.

Fertility

Cancer and cancer treatment can sometimes damage the reproductive organs such as the ovaries and testicles. These changes can have short or long-term effects on your fertility (the ability to get someone pregnant or to get pregnant and carry a child to a healthy birth). Talk to your doctor before treatment starts if you would like to have a child in the future.

AHS Fertility Services



www.readyornotalberta.ca

If you would like more information, see the Fertility and You booklet





A4. Know who is on your care team

You are at the centre of your healthcare team. Our doctors, nurses, and other healthcare providers work together with you. Often, many doctors, specialists and nurse practitioners work together to create a treatment plan even if they are not seeing you during appointments.





You may have different healthcare providers as part of your team depending on what treatments you have and what support makes most sense for you. The members of your team may change during your care if your needs change.

Your Healthcare Team will Include:

You and Your Family

You are at the centre of your care team. Please:

- Let us know how your are doing at each appointment
- Ask us your questions
- Let us know if you are or think you might be starting to have a side effect from treatment.
- Be sure to tell us if any of your medications have changed, if you have been to the emergency room since we last saw you, or if vou've had a fall.

Hearing how you are doing and what questions or concerns you have helps us provide the best care possible. If we know what matters to you with each visit we can help provide the support, information or even referrals you need.



"Family" means anyone you identify as important and would like included in vour healthcare visits. This can include people who are not legally related to you.

Cancer Doctor (Oncologist/Physician)

There are different types of cancer doctors (oncologists). You may see a:

- Medical Oncologist (systemic treatment doctor)
- Radiation Oncologist (radiation treatment doctor)
- Surgical Oncologist (surgeon)
- Hematologist Oncologist (blood cancer doctor)
- Gynecologist Oncologist (surgeons who also prescribe systemic treatment for cancers that affect female reproductive organs)

They will tell you your treatment options and the risks and benefits. The doctor makes the treatment plan with you.

Some of our centres are teaching facilities. Students, interns and residents may be involved in your care. **Please ask** the healthcare team questions if you are unclear about who people are or what their roles are.

Family Doctor

Helps manage your health before, during and after treatment. If you don't have a family doctor, there are several ways to find one:



811 (Health Link) www.albertahealthservices.ca » find a doctor

Nurses

Nurses work to coordinate your care. They teach you about cancer, tests, treatments, give medications, and will work with you to manage your concerns and symptoms. They also direct and connect you to other members of your healthcare team as needed.

There are many different nurses working in a variety of areas including outpatient treatment and clinic areas, inpatient units and clinical trials.

Clerks

Main reception clerks greet and direct you to where you need to go. Specific clerks book your appointments, notify you of any changes and check you in when you arrive for your appointment in that area.



This will depend on what treatments you are on and what supports you need.

Cancer Patient Navigators

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

- work at the community and regional cancer centres.
- guide patients through cancer tests, appointments, treatments.
- support care closer to home when possible.
- help patients and families before, during and after treatment.

If you live near a regional or community centre, ask your doctor or clinic nurse at your next visit how you can get in touch with them, even if you are not being treated at a centre farther away.

We also have Cancer Patient Navigators who work with specific groups of people:

Adolescent and Young Adult (AYA) Navigators

Work to ensure that young adults (ages 17 to 39 years old) experiencing a cancer diagnosis have access to information, supports, or referrals that may be helpful or important to them. They:

- help patients identify individual concerns
- provide education and support
- link AYAs to hospital and community support resources
- connect AYAs to young cancer peers



Indigenous Cancer Patient Navigators

Provide other supports to Indigenous patients and families throughout the province. They:

- talk about cancer and treatment plans
- advocate for patients, and help answer questions about what to expect
- help health professionals to better understand Indigenous peoples, and their cultural ways
- connect clients to services, supports and resources
- find cultural peoples to help facilitate cultural practices



Dietitians

Registered dietitians are experts in food and nutrition. They help people with healthier eating patterns and lifestyles to prevent and treat chronic diseases. They can give you advice and help you manage any problems you may have with eating and nutrition during treatment. Ask your cancer doctor or nurse for a referral to see a dietitian.



Drug Access Coordinator

Many supportive medications, such as anti-nausea drugs or blood thinners, are not covered by Alberta Health Care. Without a drug plan, these prescriptions can be very expensive and patients can face thousands of dollars' of medication costs.

Your Drug Access Coordinator can talk with the drug company to see if there are any programs that cover, or share the cost of the drug.

Interpreters

Alberta Health Services offers interpreter services by telephone. Staff can call the "Language Line" and connect with an interpreter. You will also be given a phone to join the conversation and hear the translation from the interpreter.

Find resources in English, French and Chinese on the Canadian Cancer Society website.

Nurse Practitioners

Nurse practitioners (NPs) are registered nurses who have additional education and nursing experience, which gives them the ability to:

- diagnose and treat illnesses
- order and interpret tests
- prescribe medications
- perform medical procedures

Nurse Practitioners collaborate with oncologists as part of your care team.

Cancer Care Alberta Pharmacists

The pharmacists fill your cancer medicine prescriptions, answer questions about your current medications and provide information about your cancer medicines and their effects.

Radiation Therapists

The radiation therapists plan your radiation treatments with the radiation doctor. They will also talk with you about what to expect during radiation treatment, give you the radiation treatments and help you manage any concerns.

Rehabilitation (Rehab) Oncology Specialists

Cancer and cancer treatment can cause physical changes that affect how your body functions. Rehab Specialists can help with conditions like lymphedema and peripheral neuropathy. Sometimes, everyday activities, such as feeding or dressing yourself may become difficult.

Rehabilitation or "Rehab" specialists can help with these concerns. Types of specialists include:

- Physical Therapy (PT)
- Occupational Therapy (OT)
- Speech Language Pathology (SLP)

Some cancer centres have their own rehabilitation (rehab) staff, while others work with rehab specialists in their community. Talk to your cancer care team if you think rehabilitation may be right for you or to get a referral.



Psychosocial Oncology Specialists Psychologists and Psychiatrists



These professionals offer counselling or therapy to patients and their families to help reduce emotional distress and explore ways to cope. They:

- · Facilitate support groups.
- Help individuals or families with things such as communication, stress, coping with treatment side effects, mood changes, quality of life, body image or loneliness.

Social Workers

- **Resource Social Workers** provide practical support and information on resources about discharge planning, finance, personal affairs, transportation, accommodations, long-term placement and other non-medical concerns.
- Clinical Social Workers offer counselling to patients and family members to help reduce emotional distress and explore ways to cope; facilitate support groups.

Spiritual Care Providers/Counsellors

- Help people explore their beliefs, values, and emotions as they consider what gives them hope and comfort while living with cancer, grieving losses, and seeking meaning.
- Offer support to all, whether religious or non-religious.

Most healthcare centres have a Prayer and Reflection room. These areas offer a peaceful space for prayer, meditation, reflection or a quiet break.

Volunteers

Volunteers generously give their time and energy to help patients find their way, serve refreshments, prepare patient information packages, operate the gift shops, as well as many other things. If you are interested in learning more about the volunteer programs, visit www.albertahealthservices.ca/volunteers/

A5. Find out information about your cancer centre

We will give you more information about the cancer centre you will be visiting. Ask for a pamphlet called "Getting to Know Your Cancer Centre" or view it online at

www.cancercarealberta.ca

> Information for Patients and Families > Just Diagnosed > Cancer Centre Information



For other online sources:

- Other health program and service information can be found on the Alberta Health Services website at www.albertahealthservices.ca/info/Page15145.aspx. Click the "Health Care Locator" to search hospitals and facilities or for more programs and services.
- For quick links and other health resources, visit the Information for Patients and Families page at https://www.albertahealthservices.ca/info/Page12623.aspx

В

Understanding Your Diagnosis

It can be hard to remember everything you hear. Make a plan to help. You can:



Bring someone with you



Take Notes



Audio record with the *My*Care Conversations app

B1. Learn the basics of cancer

It is very hard to hear the words "you have cancer." It can be a difficult and confusing time. It's important to understand what cancer is, so you can better understand your options and make decisions about your treatment.

Healthy cells dividing:

What is cancer?

Our body is made up of many cells. **Healthy cells** know when to divide and when to die.

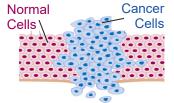






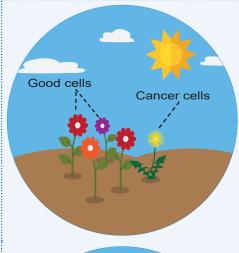






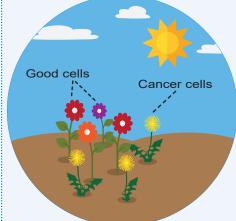
Cancer happens when cells start to grow out of control. When these cells grow and divide, they can form a lump called a **tumour**. Not all tumours are cancer. Some are non-cancerous (also called **benign**).

It might help to use the example of a garden:



A Healthy Body

Imagine your body as a garden. The soil is your immune system, the good plants are your good cells, and the weeds are the cancer cells. When you're healthy, the good plants grow and the soil helps keep the weeds away. When the odd weed starts to grow, the body is able to get rid of it by itself.



A Body with Cancer

Cancer cells are like weeds in your garden. Sometimes the body cannot get rid of the weeds and needs help.



Types of Cancer

There are over 215 types of cancer and even each type of cancer can be different depending on what **stage** and **grade** it is at.

- Stage of a cancer the size of the tumour and how far it has spread from where it began
- Grade of a cancer how the cancer cells look (under a microscope)

Determining the stage and looking at the grade of the cancer helps doctors recommend what type of treatment would be best. The doctor will also consider any other health conditions you have, whether you have had cancer or cancer treatment before and your specific concerns.

We are here to support you in whatever way we can. You may get lots of different advice from well-meaning family, friends and even strangers. Not everything that someone else has experienced will work or make sense for you, even if they have the same type of cancer. Make decisions that are right for you.



Stages of Cancer

Stage 0 – abnormal, cells that look like cancer have started growing

Stage 1 – the cancer is bigger than Stage 0 but still small enough that it is still where it started and hasn't spread anywhere else

Stage 2 – the cancer has grown deeper into the tissue, but hasn't spread to the lymph nodes

Stage 3 – the cancer is larger and may have spread to the tissues nearby, the lymph nodes (part of the lymphatic system), or both

Stage 4 – the cancer has spread from where it started to at least one other body organ; also known as "secondary" or "metastatic" cancer

Grades of Cancer

Grade 1 – cancer cells that look similar to normal cells and are growing slowly

Grade 2 – cancer cells that don't look like normal cells and are growing faster than normal cells

Grade 3 – cancer cells that look abnormal and may grow or spread more quickly



B2. Ask questions about your cancer diagnosis

It's important to make sure you have all the information you need. Listen carefully and share any concerns you have with your doctor. Tell the doctor If you do not understand what they are saying and ask them to explain things in a different way. Get the information you need by asking questions that are important to you.

Prepare questions before you talk with your doctor. You may want to ask questions like: ☐ What kind of cancer do I have, and where did it start? ☐ Has the cancer spread to other parts of my body? ☐ How advanced is my cancer?





B3. Connect with trusted sources of information

Cancer Care Alberta (CCA) Website (see page 1 for information about CCA)

Find information, contact numbers and resources online at:



www.cancercarealberta.ca

Cancer Glossary (Word Meanings)

Wondering what a cancer-related word means? Search for a word to find out what it means or browse a list of terms from the drop-down menu to find out what it means.

Canadian Cancer Society



https://cancer.ca/en/cancer-information/resources/glossary

National Cancer Institute



https://www.cancer.gov/publications/dictionaries/cancer-terms

Pauktuutit Inuit Women of Canada

Kaggutiq Inuit Cancer Glossary - Review general cancer terms or use the table of contents to choose specific cancers.



pauktuutit.ca/kaggutiq

Knowledge Resource Services

 AHS Knowledge Resource professionals have a number of website 'Best Bets'



bit.ly/tipsonline2



Canadian Cancer Society (CCS) Information Specialists

This is a national, free service provided by CCS. Information Specialists answer your questions about cancer in a clear way in English or French (for other languages an interpretor service will be used). They also help connect you with other types of support.



1-888-939-3333









If you find information that is new or different than what you were told at the cancer centre, talk to your healthcare team. They can help confirm, clarify or correct information and help relate information to your diagnosis and treatment.

Recommended Websites

General Cancer Information

MyHealth Alberta	myhealth.alberta.ca	
Canadian Cancer Society	cancer.ca	
BC Cancer Agency	bccancer.bc.ca	
Canadian Cancer Survivor Network	survivornet.ca	
American Cancer Society	cancer.org	
Cancer's Margins	lgbtcancer.ca	
Oncolink	oncolink.org	

Cancer Types

Bladder Cancer Canada	bladdercancercanada.org	
Brain Tumour Foundation	braintumour.ca	
Canadian Breast Cancer Network	https://www.cbcn.ca/en/	
Canadian Skin Cancer Foundation	canadianskincancerfoundation.com	
Carcinoid Neuroendocrine Canada	cnetscanada.org	
Colorectal Cancer Canada	coloncancercanada.ca	
Foundation for Women's Cancer	foundationforwomenscancer.org	
Gastric Cancer Foundation	gastriccancer.org	
Head and Neck Cancer Alliance	headandneck.org	
Kidney Cancer Canada	kidneycancercanada.ca	
Leukemia & Lymphoma Society of Canada	llscanada.org	
Life Beyond Lymphoma	lifebeyondlymphoma.ca	
Lung Cancer Canada	lungcancercanada.ca	
Melanoma Network of Canada	melanomanetwork.ca	
Myeloma Canada	myelomacanada.ca	

Pancreatic Cancer Canada	pancreaticcancercanada.ca	
Prostate Cancer Canada	prostatecancer.ca	
Sarcoma Cancer Foundation	sarcomacancer.ca	
Thyroid Cancer Canada	thyroidcancercanada.org	
Testicular Cancer Canada	testicularcancer.ngo	
Ovarian Cancer Canada	ovariancanada.org	







For information on specific cancer types:

www.cancercarealberta.ca
> Patients and Families > Just Diagnosed > Cancer Types





Deciding On and Starting Treatment

C1. Understand the types of treatment



There are many different types of cancer treatments including: systemic treatment, radiation treatment, surgery and stem cell transplant. Not all of these might be options for you. To learn more about how a treatment plan is made for you, see the next section.

Once a treatment plan is made, we will give you a book that tells you more about that type of treatment.







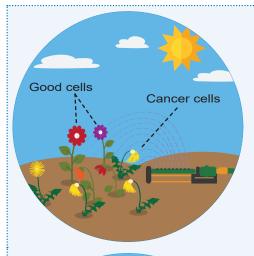


Systemic Treatment

Systemic treatment is any medication that travels through your body in the bloodstream to find, damage and destroy cancer cells. This medication can also affect healthy cells in your body. Systemic treatment can be used alone or combined with other treatments.

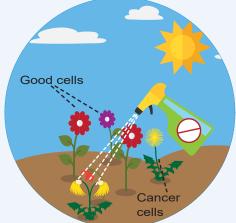
Types of systemic treatment include:

- chemotherapy
- targeted therapy
- immunotherapy
- hormone therapy



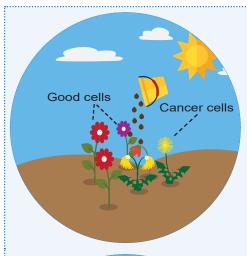
Chemotherapy

Chemotherapy is like spraying a weed killer on the whole garden. The goal is to kill the weeds, but sometimes some of the healthy plants are also affected.



Targeted Therapy

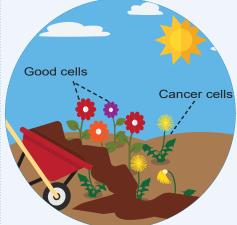
Weeds are directly sprayed with weed killer. Good plants may still be damaged.



Immunotherapy

Immunotherapies are like adding a fertilizer to the soil. They make the soil (immune system) stronger to restore the garden's health and remove the weeds.





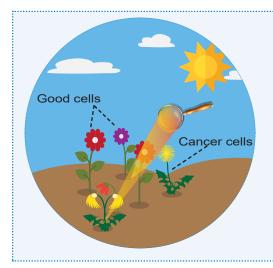
Hormone Therapy

Hormone therapy is like spreading mulch on the garden. The mulch blocks the sunlight and air that the weeds need to grow and stops more seeds from taking root.

Radiation Treatment

Radiation treatment is a cancer treatment that:

- Uses high energy x-rays to get rid of cancer cells or shrink tumours
- · Treats many types of cancer as well as some conditions that are non-cancerous
- Can be used alone or combined with other treatments such as surgery, or chemotherapy.



Radiation Treatment

Radiation treatment is like increasing the power of the sun with a magnifying glass and aiming it at the weeds. The goal is to damage the weeds in order to get rid of them, or prevent them from growing or making new weeds. Sometimes other healthy plants nearby might get damaged as well.

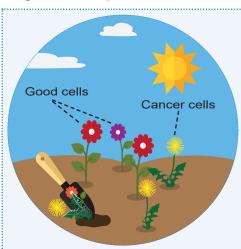
Continued next page

Surgery

Surgery involves cutting out the cancer and some of the healthy tissue around the cancer. The amount of tissue taken depends on the size of the cancer. Sometimes surgery is the only treatment a person needs. Other times systemic or radiation treatment are also needed. If you need surgery, your surgeon will talk with you about your options.

Certain types of day surgeries to treat cancer are performed at our cancer centres, but most surgeries take place at other local hospitals.



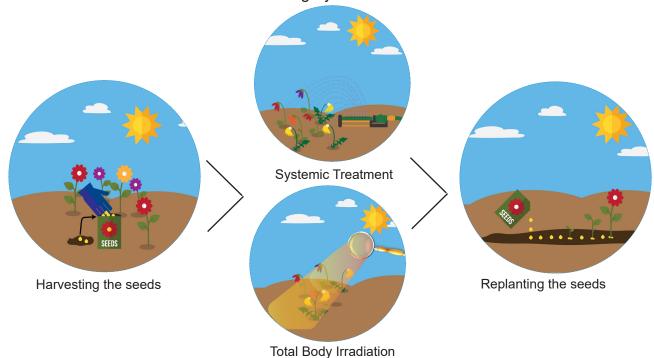


Surgery

Surgery takes out the weeds and some of the healthy plants and soil around them. How much depends on the size of the weed.

Stem Cell Transplant (SCT)

Some people require blood and marrow stem cell transplants as part of their treatment. A specialized team supports your care during this treatment. Some types of transplants are done in Edmonton while others are done in Calgary.



Stem Cell Transplant (SCT)

SCT removes the seeds (new good cells) and stores them. Then the garden is treated with chemotherapy or radiation (or both), which kills both the weeds and the good cells. Seeds are then replanted so the garden can start new.

C2. Make a treatment plan

How a Treatment Plan is made

We need many different types of doctors, nurses, and other care providers to help treat people with cancer. In the cancer program, we are organized into teams of many different types of care providers called multidisciplinary teams. This helps us give you the best care possible.

Research has shown us which treatments work best for different types of cancer. By working together and using this evidence and research, we are able to recommend the best treatment plan for you.

There are many things to consider when making a treatment plan. These include:

- 1. The type of cancer and where it is in your body
- 2. Any other medical conditions you may have
- 3. Whether you have had cancer treatment before
- 4. Provincial guidelines for treatment (www.albertahealthservices.ca/info/cancerguidelines.aspx)
- 5. Your personal wishes and goals

Your doctor will talk with you about your treatment plan, answer your questions, and work with you to decide on the best plan for you and your goals.

Complex case review

Complex cases are cases that include other things that might make planning your treatment more difficult. When we get a complex case, we talk about it at a meeting called the **Multidisciplinary Tumour Board Rounds**. This may happen before you come to your first consult, or at another time during your treatment.

At the case review, doctors and nurses from different specialties review your medical history and test results. This information helps them look at the best way to manage your care.

We do not review all cases at this meeting. It is okay for you to ask your oncologist if your case was reviewed. If it has, you are welcome to ask what was recommended.

If you are unsure of what your doctor has recommended for you for treatment, ask if your case was discussed at one of these case reviews.

- If it was, then please know that a team of doctors and other healthcare providers reviewed your case and created a treatment plan for you. They may have also recommended more tests for you if needed.
- If your case was not discussed, ask your oncologist if this review would be helpful. The
 results of the discussion will be reported back to you. This may delay the start of your
 treatment for a short time.



Concerns

We welcome you to talk about your concerns with your doctor and nurses. Maybe something your doctor told you seems different than what you were told before, or you do not feel like your wishes have been respected. We want you to feel comfortable talking about your concerns.

Often concerns can be managed by talking with your doctor or nurse. Our healthcare teams want to know about your concerns so they can do their best to work out a solution. If you do not have enough time during your clinic visit to talk about your concerns or ask questions, ask for another appointment or phone call.

(C)

If you feel you cannot continue with your doctor, you may ask to see another doctor. Changing doctors can take time and it's important to know that you may need to:

- Continue working with your current doctor until the changes are made.
- Have your care at a different cancer centre if your doctor is the only one who treats your type of cancer or provides a certain type of treatment.

Goals of treatment

The goals of treatment are different for everyone, even for someone with the same type of cancer as you. This is because the stage and grade of their cancer or their personal wishes for treatment may be different than yours.

The 3 goals for treatment are to:

Become cancer-free — to get rid of the cancer from your body
Get control — to stop the cancer from growing and spreading to other parts of your body (non-curative; palliative)
Relieve or reduce symptoms the cancer may cause such as pain, or shortness of breath (palliative)

Monitoring Your Health (Imaging Tests and Lab Work)

You have had many tests to help find out the type of cancer you have and where it is in your body. These tests include imaging tests so we can see where the cancer is and what parts of the body are affected. Tests also include blood tests.



We monitor your progress and overall health with these tests. Usually, your schedule for tests depends on the type of treatment you are having.

C3. Learn about clinical trials

Clinical trials are studies that test different treatments or supports. Patients volunteer to participate in these studies. Since teaching and research is important, we run many different clinical trials each year.

For more information about trials or to see which ones are active now in Alberta, visit:



www.albertacancerclinicaltrials.ca

C4. Ask questions about your cancer treatment

It's important to make sure you have all the information you need. Listen carefully and share any concerns you have with your doctor. Tell the doctor if you do not understand what they are saying and ask them to explain things in a different way.

My Treatment Worksheet



Get the information you need by asking questions. Consider asking the ones on page 53. Write down your questions before you talk with your doctor.

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C5. Manage concerns and track symptoms

Possible Symptoms and Side Effects

Cancer and cancer treatments can cause you to feel unwell. The symptoms or side effects you experience will depend on many things including your general well-being, where your cancer is and what treatments you are on.



Side Effects Caused by Treatment

Most side effects are specific to the type of treatment you get. Your doctor will talk with you about what side effects your treatment could cause and how you might prevent, reduce or manage them. For more information on side effects and how to manage them, look at our treatment books, or our booklets on certain side effects (such as constipation, or diarrhea). Ask for these at your cancer centre or look online:



www.cancercarealberta.ca > Patients and Families > In Treatment > Managing Side Effects

General Side Effects

There are a few general side effects, such as emotional challenges, intimacy and sexuality, and fatigue that people have no matter what treatment they are having. Find resources and tips for reducing or managing these:

emotional challenges	→Page 34 in this book →www.albertahealthservices.ca/cancer/Page16325.aspx	
effects on intimacy and sexuality	 →Page 41 in this book →www.albertahealthservices.ca/cancer/Page16317.aspx 'sexual health' →www.myhealth.alberta.ca » ('cancer and sexuality' 	
• fatigue	 →www.albertahealthservices.ca/cancer/Page16317.aspx 'fatigue' →www.myhealth.alberta.ca » Ç 'cancer and fatigue' 	



If what you are trying is not helping or you are concerned about your symptoms while on treatment, talk to your healthcare team or call the contact numbers you are given.

Palliative Care

Palliative care is an added layer of support for you and your family that can be used before, during or after treatment ends. It is often misunderstood and is sometimes thought of as a negative or scary thing. In fact, palliative care can provide many benefits to both patients and families at any stage of your cancer care. It can be provided along with treatment for the cancer or by itself.



Improves Helps with **Palliative** quality of life by: practical concerns by: care can managing symptoms providing support with goals help such as pain and nausea of care decision making and patients addressing anxiety, advance care planning depression or and Supports people coordinating spiritual concerns families around the end referrals of life by: live life to explaining what to the fullest. expect at end of life Palliative connecting to grief care: support

Who provides palliative care?

Your current care team can provide some palliative care. There are also specialized palliative care teams (doctors, nurses, social workers and other professionals) who work together with you, your cancer doctor and your family doctor to focus on the issues important to you. This team works with you to make care plans based on your values, preferences and wishes. In some centres this group is called the "Pain and Symptom Management" team.

Where can I get palliative care?

Palliative care is available in the home, community, nursing homes, outpatient clinics and hospitals. If you think palliative care may help you, ask your care team for more information or try these resources:

Alberta Health Services — Palliative Care

Health care services for people needing palliative care and their families. Information and links to resources by area are available.





Living My Culture

Quality palliative care that helps you honour your culture, spirituality and traditions. Stories and wisdom about living with serious illness, end of life, and grief to support others offered by people from various cultures.



www.livingmyculture.ca

MyHealth Alberta

Information, resources and tools about all aspects of palliative care.



myhealth.alberta.ca » Q Palliative and End of Life Care

Monitoring How You Are Feeling

We want to understand and track how you are doing at every appointment. We do this through our conversations with you, and with lab or diagnostic tests. To do this, we use a **Patient Reported Outcome** questionnaire called the **MySymptom Report**. It helps us:

- see how you are doing at the beginning of an appointment
- monitor how your symptoms are changing over time
- work with you to address any concerns or side effects

You may be asked to complete the **MySymptom Report** questionnaire for most of your appointments. You can complete this questionnaire online in your **MyAHS Connect** account up to 3 days before your appointment. If you cannot complete it online, you may get a paper version.





MySymptom Report

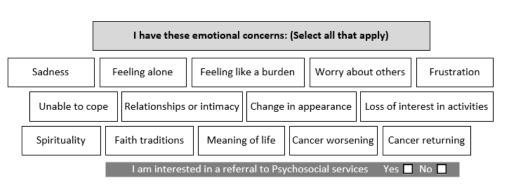
The first section of the MySymptom Report has 15 symptoms that are commonly experienced. Rate these on a scale of 0-10, with 0 being no symptom and 10 being high symptom distress. The table below can help you rate your symptoms from 0-10.

None	Mild	Moderate	High
Symptom Rating 0	Symptom Rating 1-3	Symptom Rating 4-6	Symptom Rating 7-10
I do not have this symptom	I am able to manage this symptom well	I am not able to manage this symptom	I am in serious distress or discomfort
	I can still do daily functions or activities	It is hard to do daily functions or activities	I cannot do daily functions or activities
	This symptom does not affect my quality of life	This symptom affects my quality of life	This symptom significantly affects my quality of life
		It is hard to think about anything else because of this symptom	I cannot think about anything else because of this symptom

MyPersonal Needs

The second section is called **MyPersonal Needs**. When you are completing the questionnaire online in **MyAHS Connect**, it may ask you for more information based on your symptom ratings in the first section. Here is an example of what it might look like:

You can check off your concerns, and whether you would like to have a conversation with your care team about a referral to supportive care services. If you and your care team are not able to talk about all of your symptoms or concerns at your appointment, decide on the next steps together.



If you feel your care team **is not reviewing or discussing** your symptoms and concerns with you, please speak with them.

We also use this Patient Reported Outcome information across the province to look at group trends and help us make plans to better meet patients' needs.



Do you have concerns managing your symptoms? Find resources online:



www.ahs.ca/cancertreatment > Managing Side Effects





Staying Safe

Safety is a part of everything we do in cancer care. There are many things you can do to help you stay safe.

D1. Prevent infections

You can be more at risk of getting an infection when you are sick or when you are having certain cancer treatments. There are a few ways that staff, patients and families can reduce spreading infections to others.



Cleaning your hands

This is also known as **hand hygiene**. It is the best way to prevent germs from spreading. Use hand sanitizers often, especially on the way into and out of our centres. Using soap and water is best before preparing food and eating, when hands are visibly dirty, and after using the washroom.



Immunizations

Regular immunizations, like the flu shot, are a part of managing your health. Live vaccinations are not recommended during treatment. Talk to your healthcare team about what immunizations are right for you. Here are the healthcare provider guidelines: www.albertahealthservices.ca/assets/info/ hp/cancer/if-hp-cancer-guide-supp002-vaccination.pdf



Protecting others if you might have an infection

Cancer treatments can weaken your immune system and make it easier for you to get sick while you are on treatment. Tell us if you are sick before your appointment, so we can better protect your health and the health of others.

Call the cancer centre if you have an appointment and have any of these symptoms:

- Fever
- Sore throat
- Any other cold symptoms

- New rash
- Diarrhea
- Uncontrollable vomiting

- New cough
- Runny Nose

D2. Communicate what's important

Things You Should Know

Telephone Messages



We want to make sure your messages from us stay private. This is why calls from our clinics and centres will display as only "Alberta Health Services", or a "private caller." To make sure you get the messages you need from us, we ask that you:

- Do not subscribe to a service that does not allow unknown or private callers to reach you
- Say your name clearly on your message greeting so that we are sure we are reaching the right person

Identification (ID) Cards



You will be asked to show 2 pieces of ID when you come. We double-check who you are because it's important you get the right treatment.

When you show us a piece of ID, we will ask to confirm 2 things on the card. For example, we may ask you to spell your last name or tell us your birth date.

Cancer Care Contact Numbers



It's important to know who to call if you need help. If you are on systemic treatment, your nurse will give you a contact card with a "Telephone Triage" number. If you are on radiation treatment, your radiation therapist will

My Cancer Care Contact List



give you a business card with a phone number. Other numbers can be found in the "Getting to Know Your Cancer Centre" pamphlet or with an online search for specific AHS programs or services (see page 9).

Things You Should Tell Your Team

Pregnancy



If you think you are pregnant, talk to your doctor **before** you start any treatments. Treatments when you're pregnant can affect the unborn baby.

Some treatments can affect your ability to have biological children later on — this is for **both men and women**. Talk to your doctor about your options are for preserving your fertility **before** you start treatment.

Both men and women should use some form of birth control before and during treatments to prevent pregnancy.

Ask your doctor when it would be safe to try to become pregnant after treatment.

Medical Devices



Let your care team know if you have any medical devices implanted in your body. We need this information to plan your treatments so they will not cause problems with these devices.



Complementary and Integrative Medicine



Tell your doctor or nurse about anything you are taking or using. Some complementary medicine may make your treatment less effective. It can include things like:

- pills
- · vitamins
- massage
- hyperbaric oxygen treatment
- injections
- · herbal remedies
- · acupuncture
- cannabis (look for the booklet called Medical Cannabis and Cancer)



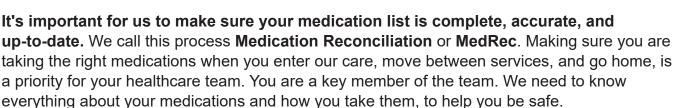
It's always best to talk to your healthcare team before you start using any complementary and integrative medicine.

D3. Understand your medications

It's important for you to know and understand all the medications and herbal supplements you are taking. You should know:

- · why you are taking the medicine
- what it is used for
- how long you will be taking it. For example, antibiotics may be used for a short amount of time, while you might take a blood pressure medication for a long time.
- what foods or other medications to avoid while taking it (if any)

If you're not sure, it might be time to review the medications you are on. Talk with your healthcare provider or ask a pharmacist to review them with you.





- Make an up-to-date list of all your medications (including any herbal or "natural" supplements).
- Keep your medication list somewhere you can find it to take to appointments or if you need to go to the hospital (on the fridge, in your purse).
- Review the list regularly to make sure you know what you are taking.
- Review the list with your healthcare provider at every medical appointment to make sure you are still taking the medications you need.
- For tools, tips, resources, videos and tracking worksheets:

 myhealth.alberta.ca » amedication list







D4. Keep your environment healthy and safe



Preventing Falls



Slips, trips and falls can happen to anyone. It is important to do what you can to prevent a fall.

- Resource: Take Action Prevent a fall before it happens www.bit.ly/AHSPreventsFalls
- · Tell your healthcare team if you have a fall.

Plants and Pets



Live flowers and plants carry germs that may be harmful to patients. No live flowers or bouquets are allowed in cancer centres.



Pets are not allowed in cancer centres because there is a risk that they can bring germs into the centre. Service animals with proper documentation are welcome.

Scent Free Environments



Many people are sensitive to perfumes, colognes or lotions. Once on treatment, some people have taste and smell changes and may be less tolerant to certain smells. Please help us by **not using any scented products** such as perfume, body sprays, scented deodorant, or hairspray, on days you are coming to the cancer centre. If you forget, do your best to wash it off.

Smoke Free Environments



The Cancer Centres, along with all AHS property, is smoke-free. For information on quitting, see page 44.





D5. Decide on advance care and goals of care

Advance care planning is a way to help you think about, talk about, and document your wishes for healthcare. It's a process that can help you make healthcare decisions now and for the future.



Goals of Care Designation is a medical order used to tell providers the general aim or focus of care. It is important for us to talk about these things with you when you start treatment and to update it regularly throughout.

These two conversations are separate but can be related. While advance care planning conversations don't always result in determining goals of care designation, they make sure your voice is heard when you cannot speak for yourself. A "Goals of Care" designation tells healthcare providers what level of care you wish to have.

How can I prepare?

Talk with family and friends, and consider legally naming someone as your **Substitute Decision Maker** (the person who will speak for you if you cannot speak for yourself). Make sure you complete the necessary paperwork.

Write down your wishes and talk with healthcare providers, and financial or legal professionals.

For more information:

MyHealth Alberta



tttps://myhealth.alberta.ca/HealthTopics/Advance-Care-Planning

Alberta Health Services Advance Care Planning



Government of Alberta

Personal directives and other options for making decisions about personal matters.



» Q Decision making and advance planning

Speak Up - Advance Care Planning in Canada

National interactive online workbooks, guides and resources.





A **Personal Directive** is a legal document that names the person or people you've picked to make personal decisions for you (your substitute decision maker) if you are not able to speak for yourself.

An **Enduring Power of Attorney** is a legal document that names the person you've picked to deal with your financial affairs.

Both are important to have.

Manage Your Wellbeing

Your physical, mental, emotional, spiritual, financial and social wellbeing are all related and affect one another. Taking action to focus on any one of these areas may have positive effects on the other areas and help you as you go through cancer and cancer treatment. For example, being more active can help you feel less tired.



Be Active in Your Care

E1. Know your rights and responsibilities

Patient Rights—What You Can Expect From Us

Within the healthcare system you have the right to:

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

When it comes to cancer treatment, you have the right to:

- receive and understand information about the benefits and risks of a procedure or treatment
- decide to get 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
- raise any concerns you have about the care and services you get without fear that it may affect your care
- · get the best possible health services
- · determine what health services you're eligible for
- · agree or refuse to take part in medical training or research programs

If you have something you would like us to know, please:

- · Talk with our staff
- Ask for the Manager of the area
- Contact the AHS Patient Feedback service: 🔾 1-855-550-2555
 - patientfeedback@albertahealthservices.ca





Patient Responsibilities

Appointments

It is very important that you come to all your appointments and diagnostic tests. If you cannot come to an appointment, please call the area where your appointment is, as soon as possible to reschedule. Keep in mind that if you need to reschedule an appointment, it may delay your care.

Be As Active in Your Care As You Are Able

 Talk with us if you have any questions or concerns. You are the most important member of your care team.

Living Your Best Life With and Beyond Cancer: Video Series



myhealth.alberta.ca/Alberta/cancer-lybl



- Scroll the page to see which videos interest you
- Print or download the guide on the website to help plan things you would like to try
- Attend our classes. There are many presentations for patients that are free of charge.
 Knowing what to expect and how to manage your treatments and symptoms is important.
- Use the many supportive services the cancer centre offers for you.

Respect the Privacy of Others

- · If another patient is talking with a staff member, give them privacy.
- Keep a respectful distance from reception desks when staff are serving other patients.
- Don't share the identity of other patients with people outside the cancer centre, unless they give their permission.

E2. Keep your health information safe

We collect only what we need to do our job. When possible, we work with information that doesn't include your name or other information that could identify you. Your health information may be used to:

- · evaluate your care
- gather statistics on cancer and help in cancer prevention
- conduct research if approved by an ethics committee

Just as we take precautions with protecting your health information, you should too.

- do not leave personal information lying around.
- keep your important health records and information secure and together in one place (see MyHealth Records next page)
- use a secure way to store and share clinical conversations like the My Care Conversations app (see next page).



MyHealth Records

MyHealth Records is an online tool that lets you see some of your health information from Alberta Netcare, a provincial electronic health record. When you sign up for MyHealth Records, you'll be able to see:

- the medicines you've had from community pharmacies for the past 18 months
- results for the most common lab tests from the past 18 months
- · most immunizations you've had in Alberta



Connect Care — MyAHS Connect Patient Portal

MyAHS Connect is a secure, online, interactive patient portal provided by Alberta Health Services (AHS), which gives you access to your Connect Care health information.

MyAHS Connect will allow you to:

- communicate with your AHS cancer care team
- see the appointments we schedule for you
- fill out questionnaires before your visit
- add medications you are taking and let your healthcare team verify them with you
- take care of your children or other family members from your account (proxy access)

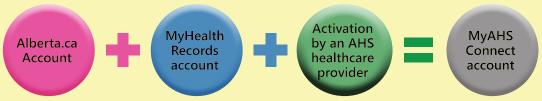
To learn more, visit: https://bit.ly/myahsconnect

There are 2 steps you need to complete **first** before you can use MyAHS Connect:

- (1) Create an Alberta.ca account
- (2) Sign up for MyHealth Records



Complete your steps today so you are ready when MyAHS Connect is offered to you!



My Care Conversations

This app is a safe way to audio record conversations with your healthcare providers. Use it to:



- remember what you talked about by audio recording your clinic conversations and listening to them later
- share recordings with trusted family and friends
- · add your own typed notes
- add questions you want to ask at your next appointment. You can select questions to appear when you start your next recording to help you remember

Download it for free from the App Store or Google Play.



E3. Communicate what matters to you

We know that cancer, and cancer treatments, affect people in many ways. Certain symptoms may be common but how they affect you and your life is unique to you. We use the best evidence to treat your cancer and support you. The best evidence includes research and expert clinical judgment, but also includes understanding what is important to you and how you are feeling.



When you share what matters to you we can:

- clarify information
- set treatment goals that make sense for you and your life
- help you manage side effects

Share what matters to you in conversation with your care team and by using the **MySymptom Report** form (see page 22).

What matters to you may stay the same or change over time. Asking for help, telling us what is concerning you or what is important to you helps us give you the best care possible.



E4. Find Information and access resources

Information and Resources

Visit www.cancercarealberta.ca for resources, support and information from prevention to treatment and beyond.

Classes and Events

Local and provincial classes, workshops and other special events are available at different cancer centres. Check with your local centre or go online for provincial events..



www.cancercarealberta.ca > Patients & Families > Classes and Events

Wellspring Alberta

Wellspring is a warm and welcoming place that offers a variety of supportive programs, at no cost, for cancer patients, their families and caregivers. They are part of a network of Wellspring centres in Canada that provide emotional, restorative and educational support programs and services to anyone affected by cancer.

https://wellspring.ca/alberta/

Alberta 211

Alberta 211 is a local resource and information service. It provides information in several ways: by phone, online or by web chat (phone service is available in many, but not all areas). We encourage local and community organizations to list their services here. This is a great place to check on what is available near you!





www.ab.211.ca to search or chat online

Search for information on things like:

- · Financial and social assistance
- Food assistance and meal programs
- Parenting and family programs
- Newcomer services
- Mental health support

- Government program assistance
- · Seniors' services and home care
- · Housing and utility help
- Disability support services

Canadian Cancer Society Community Services Locator

The CCS community services locator (CSL) is a directory that helps cancer patients, caregivers. and healthcare providers find the services they need across Canada. There are over 4000 cancer-related services listed. You can search for:

- emotional support programs
- homecare
- how to get to your cancer treatment
- · where to find a wig or prosthesis



https://csl.cancer.ca/en

Can't find what you need? 🔇 1 888 939-3333 (Monday to Friday)

E5. Attend to a terminal (end of life) diagnosis

End of life care ensures loved ones die as peacefully and comfortably as possible. Palliative end of life care can be provided in any care setting, including your home. Other care services, such as grief support, and pain and symptom management, can be arranged.

Alberta Health Services	Alberta Hospice Palliative	Canadian
End of Life Care	Care Association	Virtual Hospice
 Quick links and a list of	Provides a list of resources	Online information and
services and supports for	and services specific to	support for palliative and
your area.	palliative care.	end-of-life care, loss and
811 www. albertahealthservices.ca/info/ Page14778.aspx	 Can help you find resources in your community. 403-206-9938 www.ahpca.ca Resource Directory 	grief. • A team of experts can answer your questions about life-threatening illness and loss. www.virtualhospice.ca

For advice on talking with children about this, visit **Kid's Grief** www.kidsgrief.ca (page 47).







Live Your Best During Cancer Care

After diagnosis, you may find you are affected spiritually, emotionally, mentally, physically, financially, or practically.

F1. Cope through diagnosis and treatment

You may have big feelings such as anger, stress, anxiety, or others. These feelings are common when you or someone you love is diagnosed with cancer.

There are things you can do to help manage these feelings. Try one, and if it doesn't help, try something different. Everyone is unique but these are all things that have been helpful to others. Remember you can ask for help to identify or manage these feelings.

Did stress cause my cancer? We do not know if stress causes cancer. But, because stress is a normal part of life, it can be helpful

to find ways to

manage it.

Take control of the things you can



- Plan your days and do the things you have the strength to do.
- Eat healthy meals.
- Live a healthy lifestyle avoid alcohol and drugs.
- Try to get 30 minutes of movement a day. This will help keep your strength and energy levels up.
- Let family and friends share your responsibilities.
- Keep a journal with all your appointments and information.
- Speak to someone about spiritual supports.
- Practice mind/body activities: breathing techniques, yoga, meditation, guided imagery, soothing music, and mindfulness

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.



Get help from Psychosocial Oncology for overwhelming feelings or situations

You and your family can get free professional support without a referral.

If you've never had professional counselling you may wonder how it works. In a session you will usually:

- 1. Explore and identify concerns
- 2. Understand how these concerns relate to your life and how you think
- 3. Take action about your concerns, or learn to live with them in a different way

Psychosocial Oncology

The Psychosocial Oncology team:

- Are professionals with different specialties and may include psychologists, psychiatrists, social workers or spiritual care providers.
- Offer different supports and services to patients and family members to help reduce emotional distress and explore how to cope.
- Can help with things such as communication, stress, coping with treatment side effects, mood changes, quality of life, body image, or loneliness.
- Can also make referrals to other community resources as needed.

Call to speak with someone and find out what services are available. Visit www.ahs.ca/cancersupportivecare » Psychosocial Oncology for links to the various cancer centres or view the brochure.

Other resources

Cancer Care Alberta Classes, Groups, and Events

www.ahs.ca/cancerclasses

Help in Tough Times

https://www.albertahealthservices.ca/amh/page16759.aspx

If you have any thoughts about harming yourself or anyone else, call 911 or go to the nearest emergency room right away.

Where else can I get help?

In Crisis 911

Psychosocial Oncology



www.ahs.ca/cancersupportivecare

» Psychosocial Oncology

Mental Health Helpline (24/7)



HealthLink
Alberta

811

Canadian
Association for
Suicide Prevention

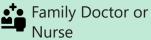


suicideprevention.ca/ help-and-information/

The Canadian Cancer Society

www.cancer.ca
» Support
Services

Your Primary Care Provider





34

Join a community or support group (in person or online)

Support groups can be a place to meet others in similar situations. Some are led by healthcare professionals while others are led by community members. They can be held in person or online. Check with your healthcare team to see if there are any local support groups that might be a good fit for you.

Canadian Cancer Society

It might help to talk with someone who has also had cancer and finished treatment. The Canadian Cancer Society's **Cancer Connection** program offers peer-to-peer support to cancer patients and their caregivers. You can talk with caregivers or current and former patients with your same type of cancer.



(2) 1-888-939-3333

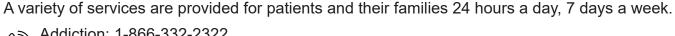


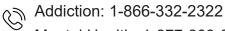
www.cancerconnection.ca

Wellspring

Wellspring is a community organization that offers one-to-one sessions with trained volunteers who have experience with cancer. Wellspring also hosts meetings for several support groups. See page 31.

Addiction and Mental Health Services (AHS)







Mental Health: 1-877-303-2642



www.albertahealthservices.ca/amh/amh.aspx



F2. Get the practical help you need

There are many practical considerations to cancer treatment. These can be challenging on their own, but there are many organizations, supports and services available to help.

Resource Social Workers

These social workers know what resources are available in your community. They can give you some direction and practical information about finances, drug coverage, transportation, Employment Insurance benefits (EI), CPP disability benefits, Assured Income for the Severely Handicapped (AISH), social assistance, accommodation, childcare and more.



Covering the Costs of Your Cancer Care

Alberta Health Care pays for the costs of treatment in most cases. However, it does **not** cover medications that you take at home to help with side effects like pain and nausea. These medications can be very expensive, so it's important to have extra coverage.

How can I cover these other medications?

You can use private health insurance to cover the costs not covered by Alberta Health Care.

If you have Alberta Blue Cross or private insurance, call and ask your insurance company:

- Do I have a yearly maximum for prescriptions? If yes, what is it?
- What is my co-pay portion?
- Is my plan a direct bill plan or a reimbursement plan?
- What level of coverage do I have? For example, is it full or partial coverage?

What if I have no drug coverage?

- You can still apply even with a pre-existing illness.
- If you have no drug coverage, we encourage you to apply for Alberta Blue Cross Non-Group as soon as possible. It will take about 3 months before Alberta Blue Cross starts covering your medicines. For example, if you apply in March you will not get drug coverage until July 1. A resource social worker may be able to help put supports in place during the waiting period. Numbers listed on page 34.
- You can find information and application forms for Alberta Blue Cross Non-Group at: https://www.alberta.ca/non-group-coverage.aspx

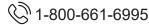
What if I need more help?

If you want help with filling out the paperwork, have more questions about what your plan covers, or need more information, call the **Drug Access Coordinator** nearest you (see page 7), or your local Social Worker.



Alberta Blue Cross

Alberta Blue Cross plans provide practical benefits you'll use on a regular basis, and affordable protection against the high cost of unexpected illness, accidents or medical conditions.





Alberta Palliative Coverage Program

This insurance plan covers most of the costs for prescription drugs for those who are dealing with a terminal illness.





Government of Alberta Resources



All of the links below can be found online at alberta.ca. Use the search term provided beside the \bigcirc symbol. Or call the toll-free number \bigcirc 1-877-644-9992.

Alberta Adult Health Benefit: can help pay for prescription drugs and other medical supplies. This service may help pay for health services not covered by the Alberta Health Care Insurance Plan. » Q Adult Health Benefit

Assured Income for the Severely Handicapped (AISH): financial and health-related support to adults with a disability. » AISH

Child Care Subsidy: helps lower income families get professional childcare services. Families must qualify and the rates will be different for each family. » Child Care Subsidy

Alberta Seniors Benefit: monthly income supplement for seniors with low incomes. » Alberta Seniors Benefit

Alberta Works: helps unemployed people find and keep jobs, employers meet their need for skilled workers, and Albertans with low incomes cover their basic costs of living.

» Alberta Works

Income Support: financial help for Albertans who do not have the resources to meet their basic needs. People who cannot work because of chronic health or other problems, may qualify for income support. » Q Income Support

1-866-644-5135 (24 hr. Emergency Support Contact Centre)

Special Needs Assistance for Seniors: a lump-sum payment to low-income seniors who qualify for the Alberta Seniors Benefit. Helps with some of the cost of appliances, minor home repairs and some health and personal supports. » Q Special Needs Assistance



Government of Canada Resources



All of the links below can be found online at www.canada.ca. Use the search term provided beside the \bigcirc symbol.

Employment Insurance Benefits

• Employment Insurance Sickness Benefit: benefits for a certain number of weeks for people who have contributed to the program. » Sickness Benefits

1-800-206-7218

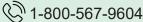
Employment Insurance Compassionate Care Benefit: up to 28 weeks of benefits for people who need to take time off work to care for a family member who is not expected to live long. » Compassionate Care 1-800-206-7218

Canada Pension Plan (CPP) Benefits

- CPP Disability Benefit: support for people who have a long-term disability and have paid into CPP. » Disability Benefit
 1-800-277-9914
- CPP Children's Benefit: provides monthly pension to the dependent children of a disabled or deceased contributor to CPP. » Children's Benefit
 1-800-277-9914
- CPP Survivor's Pension: a monthly benefit for widows or widowers of a legal or common law marriage who have little or no other income. Must be 60 to 64 years of age and have lived in Canada for a certain time. » Survivor's Pension
 1-800-277-9914
- Old Age Security Pension: monthly income for most people 65 years of age or older, who live in Canada. » Old Age Security Pension
 1-800-277-9914

Non-Insured Health Benefits Program for First Nations and Inuit

Offers information about coverage for drugs, dental and vision care, medical supplies and equipment, mental health counselling and medical transportation for First Nations and Inuit peoples of Canada. » \bigcirc Non-insured Health Benefits



Veterans' Affairs

Offers a wide range of services and benefits to qualified veterans, Canadian Forces members, some members of the RCMP, and certain civilians and their families.



Medical Equipment and Supplies

Alberta Aids to Daily Living (AADL)

- Helps Albertans with a long-term disability, chronic illness or terminal illness.
- Gives financial assistance to buy medical equipment and supplies, such as home oxygen.
- Helps with mastectomy prostheses.

You will need a medical assessment to decide what equipment and supplies you can receive.



www.health.alberta.ca » Aids to Daily Living





310-0000, then 780-427-0731 (toll-free)



Gives short-term loans of basic medical equipment to people recovering from surgery or injury, or who have problems moving on their own. You will need a referral from a healthcare provider.



www.redcross.ca » Health Equipment Loan Program

F3. Get the physical help you need

There are usually physical changes that happen when you have cancer treatment. We have specialists who can help. There is no charge for these services.

Rehabilitation Oncology

These specialists work to help you:

- improve your strength and movement
- adapt to changes in your body so you can be as safe and independent as possible
- provide relief and control of symptoms (swelling, pain, neuropathy)
- adapt to cognitive changes such as thinking, learning, or remembering information

Cancer Care Alberta offers rehabilitation support for cancer-related issues. Ask your care team for a referral.

Download the Rehabilitation Oncology brochure for more information and phone numbers.



www.ahs.ca/cancersupportivecare > Rehabilitation Oncology









Dietitians - Help you eat well

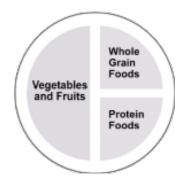
Nutrition is important in cancer care:

- People who are well nourished have a better chance of recovery, less side effects and a better quality of life.
- Cancer and cancer treatments may affect taste, smell, appetite and the ability to eat enough food.
- Good nutrition can help you deal with the effects of cancer and its treatments.

Tips for eating well



- Eat a variety of healthy foods from Canada's Food Guide each day:
 - □ protein foods
 - □ vegetables and fruits
 - □ whole grain foods
- If your appetite is low, eat small meals and snacks every few hours instead of three large meals.
- If your appetite is low or you are losing weight, choose foods that are high in calories and protein to help you maintain your weight and strength.



- For recipes, tips and food ideas, visit: www.ahs.ca/nutrition/Page16043.aspx
- Eat foods you enjoy and that taste good to you.
- Drink plenty of fluids. Aim for 8 10 cups (2 L 2.5 L) per day.
- Treat nausea and vomiting with medications prescribed by your healthcare provider.
- Talk to your healthcare provider about stool softeners and laxatives to prevent constipation.

A dietitian can give you guidance on how to eat well through treatment.

If you want more information on what to eat, drink, or both, tell your healthcare team you would like to speak with a dietitian or check to see if any nutrition classes are offered at your cancer centre. www.ahs.ca/cancerclasses

For more information:









Sexual Health

Concerns about sexuality are common during treatment.

The following resources may help:

Oncology and Sexuality, Intimacy & Survivorship (OASIS) Program

Offers resources and a patient education class for people who have sexuality and intimacy concerns.



www.ahs.ca/cancertreatment > Managing Side Effects > Sexual Health

Sexual Health Booklet Series

For more information on topics like fertility, sexual health, intimacy, and body image, ask your cancer care team for printed resources or view online.

The Canadian Cancer Society

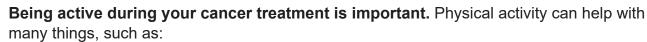
Provides information about sexuality, fertility and cancer.



www.cancer.ca » Sexuality or Fertility

F4. Be physically active

Activity and Exercise



- sleep problems
- the risk of lymphedema (swelling)
- physical fitness
- reducing treatment side effects like fatigue (tiredness), pain and nausea
- depression, anxiety and mood
- maintaining a healthy weight
- · maintaining or building strength
- · improving your body's ability to fight infection

Make sure you check with your doctor or healthcare provider before you start any physical activity.

If you are using a trainer or exercise professional, ask if they are certified and if they have exercise training specific to cancer.



If you are not exercising yet:	If you are exercising regularly:
 Do some light activity Start with something small, like a walk around the block or stretching during commercials 	You can continue! You may need to change your routine based on how you are feeling. Rest more if you are tired

Remember to listen to your body and balance activity with rest.

Choose a well-rounded program that includes aerobic exercise along with strength, balance and flexibility training.

Physical Activity and Safety During Cancer Treatment

During your treatment, we recommend physical activity. You may need to be careful if you have:

Pre-existing health conditions like low bone density (weakness of the bone) or heart problems	Ask your family doctor about any precautions you should take before increasing your physical activity.	
Taking pain or anti-inflammatory medications	These types of medications may hide or "mask" your pain. If you cannot feel pain, you may push yourself too far and hurt yourself. If you take these types of medications regularly, be careful not to "over-do-it" and take care of any injuries right away.	
Recent surgery	If you had surgery recently, talk to your surgeon about physical activity to make sure you are safe to start. You need to make sure your body is ready.	
Extreme fatigue, anemia, or peripheral neuropathy (changes in sensation)	If you have extreme fatigue (tiredness), anemia (low hemoglobin), or peripheral neuropathy (numbness in your fingers or toes), talk to your cancer doctor or ask for a referral to see a rehabilitation specialist.	

If you are working with a physiotherapist, occupational therapist, or exercise specialist, make sure you tell them about these conditions. (You may need a doctor's referral to see these specialists).



Program Options

Some options may include:

Alberta Cancer Exercise (ACE) Program

- 12-week, free exercise study program open to any person who is about to start cancer treatment, currently receiving treatment or is within 3 years of treatment finishing.
- Designed to be delivered in a community setting, and is group-based.
- Exercise is tailored to the needs of the participants and led by trained fitness instructors.



www.albertacancerexercise.com

TrueNTH (True North)

A lifestyle and supportive wellness resource for men with prostate cancer.



lifestyle.truenth.ca

University of Calgary Health and Wellness Lab

Numerous community-based exercise programs are available.



www.ucalgary.ca/healthandwellnesslab

Wellspring

Lifestyle and supportive wellness resources for people with cancer.



See page 31

Yoga Thrive

- Research-based, therapeutic yoga program for cancer survivors and their support persons.
- Gentle, 12-week yoga program modified for cancer survivors.
- Good for those with stiffness, pain, stress or fatigue.



403-210-8482



wellnesslab@ucalgary.ca



ttps://kinesiology.ucalgary.ca/labs/health-and-wellness/research/research-studies/ alberta-cancer-exercise-program-ace/yoga-thrive



Exercises for People with Cancer: 3 Minute Movement Videos



ttps://myhealth.alberta.ca/Alberta/Pages/cancer-exercise-videos.aspx



It's important to reduce your risks of developing other cancers. To learn more:



www.albertapreventscancer.ca

Practice Sun Safety



- Use sunscreen on skin not covered by your clothes that is at least 30 SPF. Check sunscreen bottles for a best before date - old sunscreen will not protect you from sun damage
- Re-apply sunscreen at least every 2 hours and after swimming or sweating
- Use sunscreen if you are outdoors even on a sunny day in winter



 Cover yourself with clothing, wear a hat and sunglasses



Seek shade especially between 10am and 3pm



For information on the health risks of indoor tanning:



https://www.healthiertogether.ca/living-healthy/ limit-uv-rays/indoor-tanning/

For employers and employees who work outdoors:



besunsible.ca

Quit Smoking or Tobacco Products

If you smoke or use tobacco products, your health care team will try to support you quitting or reducing your use. Quitting may help you have:

- A better chance of successful treatment
- Improved general health
- Fewer serious side effects
- A faster recovery from treatment
- A decreased risk of the cancer coming back, or getting another cancer diagnosis
- A lower risk of infection
- Easier breathing
- More energy
- A better quality of life

Help is available:



Alberta Quits

AlbertaQuits provides convenient options for getting help through a personalized quit plan, ongoing support and providing you with effective services in communities across the province.



Alberta Quits offers:

- · Support from trained counsellors
- · Access, day and night, to community chat forums
- · Information on medications to help you quit
- Fact sheets on various tobacco-related topics
- E-quit tips, as well as an interactive texting service

This service is free! Research shows that getting help makes you twice as likely to successfully quit. 1-866-710-7848 www.albertaquits.ca

Primary Healthcare Provider

Your primary healthcare provider or family doctor may be a member of a Primary Care Network (PCN) or Family Care Clinic (FCC) and may have access to a Smoking Cessation program for you (usually free).

Reduce or Quit Drinking Alcohol

Drinking alcohol is not recommended during cancer treatment. It increases your chances of getting certain types of cancers and can be harder on your body when it is also coping with cancer treatments. Consider limiting your alcohol intake. The Canadian Cancer Society recommends no more than 2 drinks per day for men and 1 per day for women.

1 standard drink might be smaller than you realize:

- Beer 360 mL (12 fl. oz) of regular beer (5% alcohol)
- Spirits 45 mL (1.5 fl. oz) of spirits (40% alcohol)
- Wine 150 mL (5 fl. oz) of wine (12% alcohol)



Follow these tips from the Canadian Cancer Society to help you reduce your alcohol intake:

- Plan ahead and set a limit on the amount you will drink.
- Choose the smallest serving size. Avoid double measures or specials which are often encouraged as "better value."
- Dilute alcoholic drinks, or choose low-calorie or low-alcohol alternatives.
- Do not drink alcohol when you are thirsty because you are likely to drink more.
- Keep at least a few days each week alcohol free.
- Avoid salty snacks such as potato chips or nuts while drinking alcohol. Salt makes you thirsty and more likely to drink quickly.
- Drink alcoholic beverages slowly and space out your drinks.
- Eat before and while you are drinking.
- Do not use alcohol to cope with stress. Try a walk, a bath, read a book, exercise, or listen to music to help you relax.

Adapted from: Canadian Cancer Society, 10 Smart Ways to Limit Alcohol.

https://cancer.ca/en/cancer-information/reduce-your-risk/limit-alcohol/10-smart-ways-to-limit-alcohol





Tips for Patients, Caregivers and Family

Cancer often affects the whole family and family members will often be an important part of the care team with you.

G1. Communicate with family and friends

Sharing Your Diagnosis

Find shortcuts to help you update family and friends. You might consider a blog, an email that can be sent to more people at the same time, or asking someone to communicate updates for you.

Asking for Help

You may need to rely on others for help. This doesn't mean that you need to accept everyone else's advice. Think about what is best for you and your loved one - whether you are the patient or the caregiver. Be prepared to:

- Ask for help when you need it
- Be specific in your requests of others ("could you shovel my driveway this week?")
- Be prepared to tell others "thanks, but no thanks" for their advice
- Take time for yourself

The Canadian Cancer Society provides tips and advice on how to tell family members, children, friends and co-workers about your cancer.



www.cancer.ca » Q Talking about cancer

Caregivers, family and friends may find this helpful:



www.cancer.ca » Q Listen first

G2. Talk with children and teens

Telling Children About Cancer

It can be hard to know what to say or how to talk about this difficult subject. Look at "Talking with Children about Cancer" for a list of helpful resources and materials.



www.cancercarealberta.ca > Patients & Families > Supportive Care & Living Well > Caregivers and Children



Kid's Grief

In some cases it may be necessary to talk with children about death and dying. Kid's Grief:

- can help you understand how children grieve and how to support them when someone in their life is dying or has died.
- has learning modules developed by a team of experts in children's grief, along with people who have experienced loss and supported children through grief.

It is not meant to replace professional counselling or other healthcare services.





G3. Manage your priorities and role changes

It can be hard for both patients and family members to adjust to new roles. **Changing priorities** are normal and part of the cancer experience.

When someone has cancer, priorities can change. Family members sometimes take on new roles and responsibilities. For example, children may have to help out more, or a spouse may have to help with groceries or other things. It can be hard to make these changes.

How can I adapt to my changing priorities?



Time

- Decide what's most important to you and where to focus your energy
- Give yourself and people close to you time to sort through thoughts and feelings
- Understand that for a while, some tasks may not be done as well as they were before

Talk

- Share your feelings with others. Be honest and open about how you're feeling
- Ask for help if you need it.
- Consider talking with a professional (see page 34)

Connect

- Connect with others so you can talk to someone other than family
- Try an online forum or a support group



Take care of yourself



It's important to take care of yourself too. Remember to:

- Seek support from others
- Take care of your own health so you are strong enough to help others with theirs
- · Accept offers of help
- Be specific about what others can help you with
- Write things down
- Take a break when you need it
- Get professional help if you are struggling



G4. Get support as a caregiver

Caregivers are those working hard to take care of a loved one with cancer or other health issues. Caring for someone with cancer can be difficult.

Our Psychosocial Oncology professionals are available to help (see page 34) at no cost. They will work with you on your own or with your loved one who has cancer. There are other community supports available also:

Caregivers Alberta

Support for people who provide unpaid care for a loved one living with a disability, illness or aging.

The organization offers:

- information support
- education advocacy

It helps caregivers connect with others.





1-877-453-5088 www.caregiversalberta.ca



Home Care

Alberta's Home Care Program supports Albertans through health promotion, treatments, rehabilitation and home support.



www.ahs.ca/cc/Page15488.aspx



The Canadian Cancer Society has lots of information on helping others with cancer and ways you can help yourself.



www.cancer.ca » \(\) helping someone with cancer OR » \(\) caregiver role

Respite Care

This service gives caregivers a short period of rest or relief from their responsibilities. A respite bed is provided in the continuing care area of the facility. A person can usually stay up to 6 weeks a year.



https://www.albertahealthservices.ca/findhealth/service.aspx?ld=5436

Wellspring

Wellspring is a community organization that offers one-to-one sessions for those diagnosed with cancer and their caregivers to meet with trained volunteers who have experience with cancer. Wellspring also hosts meetings for several support groups. See page 31.



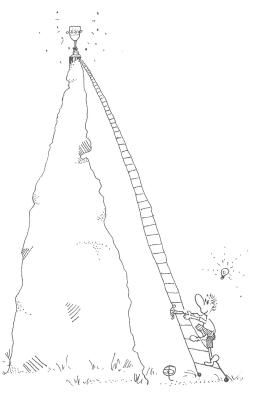
Use Helpful Tools to Take Action

After a cancer diagnosis, there are many things you will need to manage, such as:

- · attending appointments
- · making treatment decisions
- · following treatment plans
- taking care of symptoms
- · coping with emotional changes
- adjusting to lifestyle changes

While your healthcare team will manage some things for you, like scheduling appointments for treatment, these other things are managed by you and your family, in partnership with your healthcare team. Because you are taking the lead on managing these things, this is called **self-management**.

Self-management includes the skills and actions that can help you live your best with cancer. It doesn't replace medication, treatment or supportive care (like physical therapy or mental and emotional support), but it is a big part of feeling as well as you can.



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We will help you self-manage. This might include:

- talking with you about things you can do
- providing information to you that you can understand and act on
- helping you to feel confident in your ability to self-manage
- · building skills to take care of yourself

Taking action does not have to be overwhelming. Small steps can make a big difference.

Using this book is 1 step to self-manage your cancer care. You can:

- look at the Overview of Options on pages i and ii to find information and ideas for things you can do
- find specific actions you can take. These are marked with try this or try
- use the worksheets in this section to help you prepare for your appointments and get the information you need

Ask questions at any time. Remember, you are the most important member of your healthcare team and we are here to help.



H

Lists and Worksheets

H1. My checklist of what to bring

☐ This book.				
\square The site information brochure for the cancer centre I am going to.				
☐ Alberta healthcare card and photo I.D.				
☐ My Cancer Care Identification Card (If your centre uses this, you w appointment when you check in at the main registration desk.)	ill get it at your first			
 □ A list of the medicines I am currently taking: ◆ vitamins and natural health products ◆ pain medicines ◆ medicines you need renewed by your oncologist 	It can be helpful to write or type a list of your medicines and bring it with you each			
☐ Any scheduled medications I might need to take during my appointment.	time. When you are asked for it, give it to the clerk/nurse/			
☐ The list of questions I want to ask (see worksheets in this section).	doctor and ask ther to make a copy of it, so you can keep			
☐ Something to read, watch or listen to. Remember earphones! <i>Tip:</i> Download content at home as wifi at the centres can cut in and out.	your original. Be sure to update it regularly with			
☐ Something to eat or drink or money to buy something.	new medications or changes to your			
☐ My support person (family member or friend). <i>Tip:</i> It may be helpful to have them take notes during your appointment.	current ones.			
☐ My smartphone or tablet to audio record what is said during your a the My Care Conversations app for security (see page 30).	ppointment. <i>Tip:</i> Use			
☐ If I have trouble understanding English, ask staff to arrange for an i www.albertahealthservices.ca/languages/languages.aspx	nterpreter.			



H2. My cancer care contact list



My Oncologist	My Surgeon
Contact info	Contact info
Comments	Comments
My Radiation Oncologist	My Nurse(s) / Nurse Navigator
Contact info	Contact info
Comments	Comments
My Contact Outside of Regular Hours	My Other Care Provider
Contact info	Contact info
Comments	Comments
Systemic Treatment contact cards: www.albertahealthservices.ca/cancer/ Page16320.aspx	

H3. My diagnosis worksheet

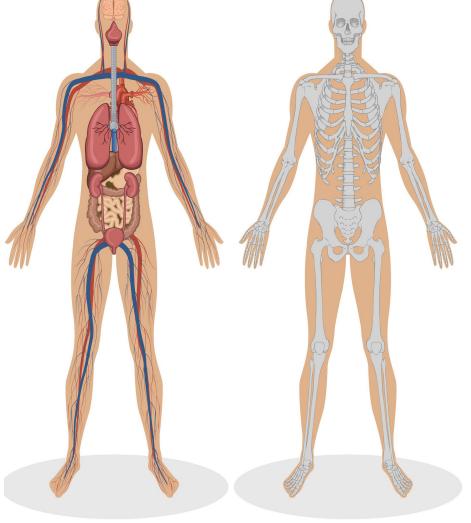
1. What kind of cancer do I have, and where did it start?

(Use the diagrams to mark down the areas of disease or treatment)



What is the name of my cancer?

2. Has the cancer spread to other parts of my body? If it has, where?



3. How advanced is my cancer?

4. What is my prognosis?

try

View these CCS resources:

- Questions to Ask
 https://cancer.ca/en/
 living-with-cancer/
 coping-with-changes/
 working-with-yourhealthcare-team/
 questions-to-ask/
 diagnosis-questions
- Cancer Types www.cancer.ca/en/ cancer-information/ cancer-type/see-all/



H4. My treatment worksheet



1. What treatment do you recommend for me?

	Systemic Treatment Type: Chemotherapy Checkpoint Inhibitor Name of medications:	☐ Stem Cell Transplant	
	Number of treatment cycles expe	ected:	_
	Radiation Treatment ☐ Brachytherapy Number of fractions:	☐ External Beam therapy	
	Surgery Type:		
	Area:		
2.	What are the goals of the treatm ☐ Become cancer-free (curative ☐ Relieve or reduce symptoms	e) 🛘 Get control (palliativ	
3.	What are the risks of the treatm	nent?	



4. If I choose not to have treatment what will happen? What other options are there?

5.	When will my treatment start? How many treatments will I have	/e?



- **6. Is there anything that I need to do before treatment starts?** (such as blood work, taking pre-medications, CT Simulation, pre-assessment clinic)
- 7. About how long will each treatment day be?
- 8. Should I have the flu shot or other immunizations?



View this Canadian Cancer Society resource:

Questions to Ask
 https://cancer.ca/en/living-with-cancer/coping-with-changes/working-with-your-healthcare-team/questions-to-ask/treatment-questions

Add more questions here:

9.			
10.			
11.		 	

H4. My safety checklist

☐ I know who my main cancer doctor (oncologist) is (complete page 51)
☐ I know who to call in case of emergency
☐ I know who to call if I have concerns
☐ I know I can ask to use the Interpreter service if I need. (see page 7)
☐ I know what each medication I take is for and how to take it (see page 25)
\square I have a list of my medications to bring to my appointments
☐ I have talked with my family about my Goals of Care and know what I want to have happe in a medical emergency (see page 23)
☐ I know what questions I want to ask about Complementary and Alternative Medicine (CAM) (see page 25)
☐ I know why hand hygiene is important in preventing infection (see page 23)
☐ I have talked about pregnancy risks with my oncologist (see page 24)
☐ I know who to call if I am sick (complete page 51)
My notes:
my notes.



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

