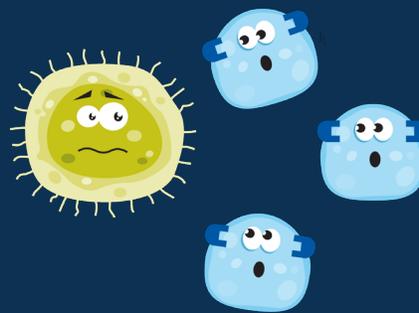


Checkpoint Inhibitors:

Information for Patients and Families



Living Your Best Life During Cancer Treatment

Treatment — Systemic



Please bring this booklet to the class and your appointments.

This booklet will help you, and your family and friends understand basic information about living your best through cancer treatment.

Read about:

- what checkpoint inhibitor treatment is and how it is used to treat cancer
- possible side effects you may have during treatment
- how to recognize the side effects
- how to manage the possible side effects with the help of your healthcare team

You do not have to read the whole book — pick and choose the sections you want to know more about when you need them.



You may be able to attend a class at your cancer centre **before you start or during** your treatment. Ask when the next checkpoint inhibitor class is.

Bring this book to:

- The class — the instructor will go over the information with the group so you will know what to do at home
- Your first treatment appointment
- And then as you need it



Terrie's Tip ~ cancer survivor:

"Information is power — the more you understand your situation, the better the partnership you create with your healthcare team."

Write your questions down in the book. If there's any information you don't understand, ask your healthcare team to review it with you.

For more information:



This book, along with other Alberta cancer care resources are available at your cancer centre or online

www.cancercarealberta.ca

Classes on nutrition, fatigue and more:

www.ahs.ca/cancerclasses

Find community support resources with **Alberta 211**

<http://www.ab.211.ca/> 211



Check out the **Newly Diagnosed With Cancer Book** if you don't already have it.

My Plan:



I will have _____ cycles.

Name of my treatment:



Write phone numbers or notes here.

Your healthcare team is here to help you and answer your questions.

Disclaimer: Products listed in this booklet are just examples, for information only. AHS does not endorse specific products.



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Tip!

Terrie's Tip ~ cancer survivor:
 "Think about creating a note book or file to keep all your information together — it will also give you an opportunity to look at past information."

A.

Just Diagnosed

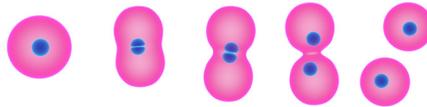


It's important to understand what cancer is, so you can understand your treatment better.

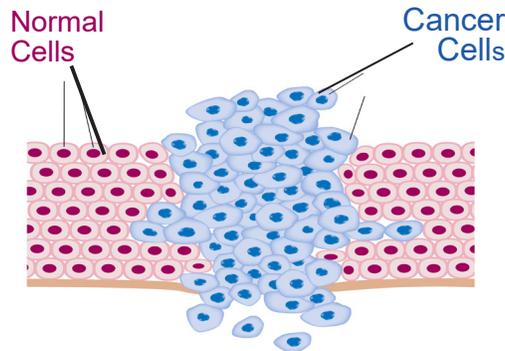
What is Cancer?

Our body is made up of many cells. **Healthy cells** follow the "rules" when they divide at a normal pace and stop growing and die when the body doesn't need them.

Healthy cells dividing:



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**).

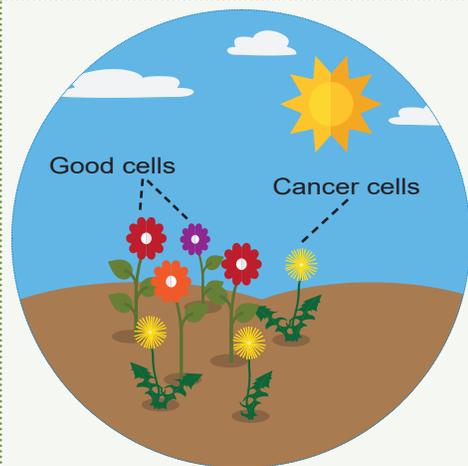


We'll use an example of a garden for a simple explanation:

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.

Image © Alberta Health Services



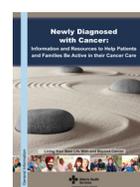
A Body with Cancer

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

Image © Alberta Health Services

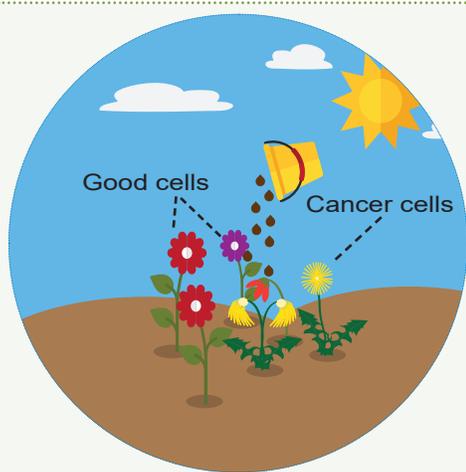
There are many different types of treatments used to treat cancer: surgery, radiation treatment, and systemic treatment.

Find out about all types of cancer treatment in the book:
[Newly Diagnosed With Cancer](#)



One type of systemic treatment is called immunotherapy. Systemic treatment is any medication that travels through your body in the bloodstream with the aim of destroying cancer cells. Systemic treatment can be used alone or combined with other treatments.

Immunotherapy is different than other cancer treatments — instead of attacking the cancer cells directly, it turns your immune system on and trains it so it so that it can attack the cancer cells. In this book, we talk about a type of immunotherapy called Checkpoint Inhibitor.



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.

Image © Alberta Health Services

Checkpoint Inhibitors

Checkpoint inhibitors are a type of immunotherapy and are different than other cancer treatments. Instead of attacking the cancer cells directly, it turns your **immune system** on and trains it so that it can attack the cancer cells.

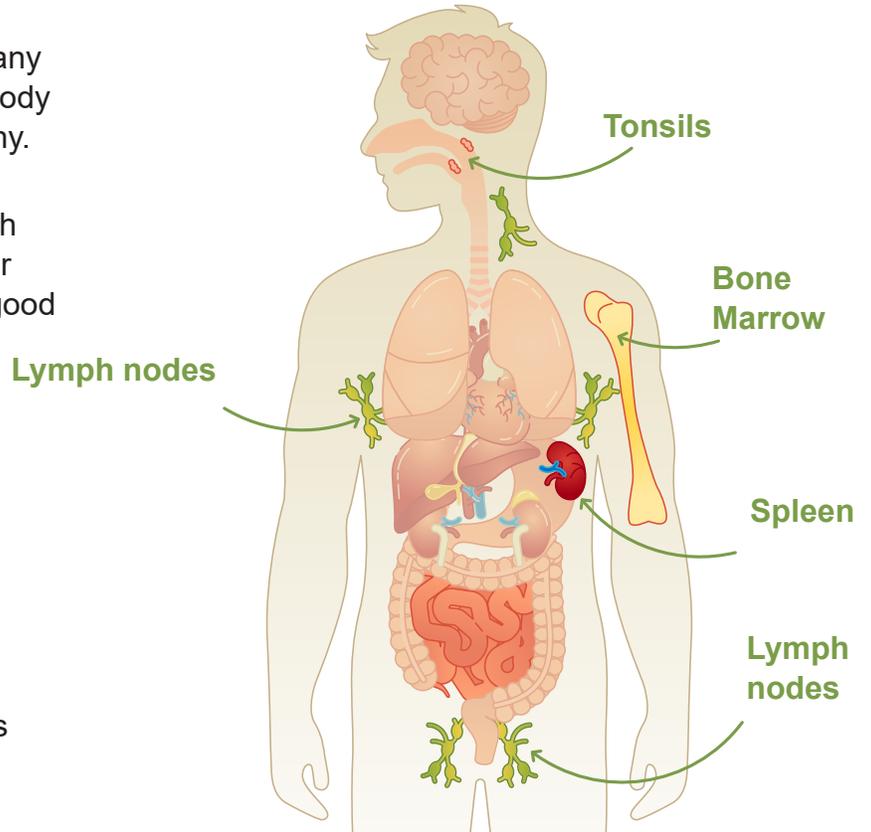
What is the immune system?

The immune system is made up of many cells and tissues found all over your body and works together to keep you healthy.

It protects the body from invaders such as bacteria, viruses, fungi (like mold or yeast), and cancer. It usually does a good job of keeping people healthy and preventing infections. Sometimes problems with the immune system happen which can lead to illness or infection.

One of the important cells is called a white blood cell (WBC). There are different types of WBCs, but the main one that checkpoint inhibitors target is called a **lymphocyte**.

The Immune System



WBCs have different jobs they do when dealing with cancer cells:



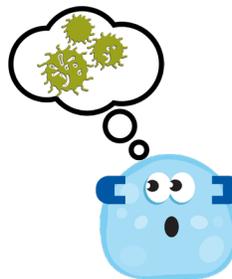
The locator — looks for cancer cells and calls other cells for more help if needed.



The helper — flags the cancer cell so that the fighter cells have an easier time finding the cancer cells.



The fighter — destroys the cells that are flagged by the helper cells.

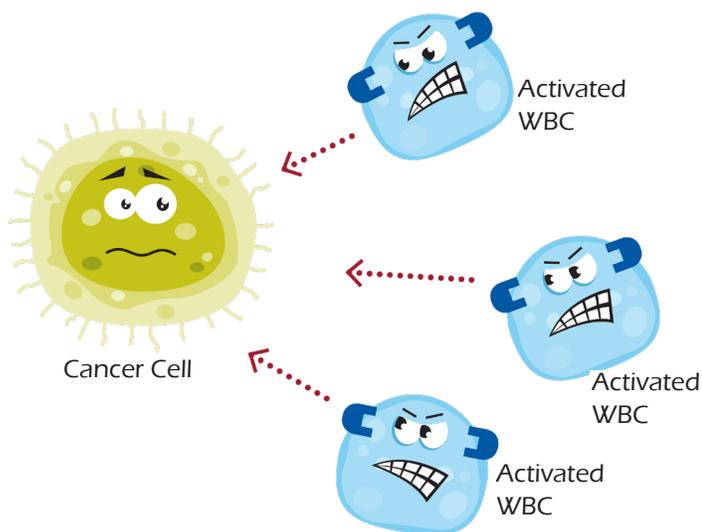
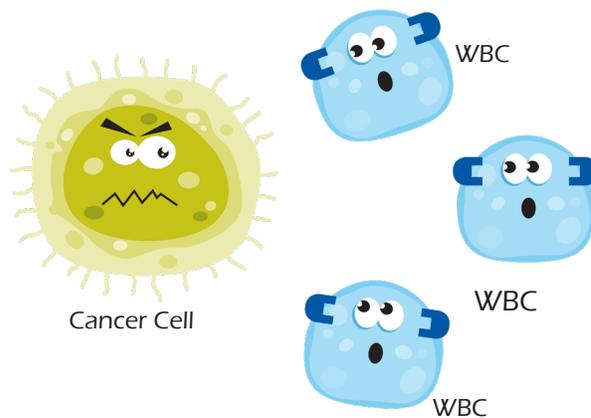


The memory — remembers what the cancer cells look like so if they show up again, the attack is quicker.

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Your Immune System — What's Supposed to Happen to Cancer Cells

WBCs recognize the cancer cell as something that is not supposed to be there...

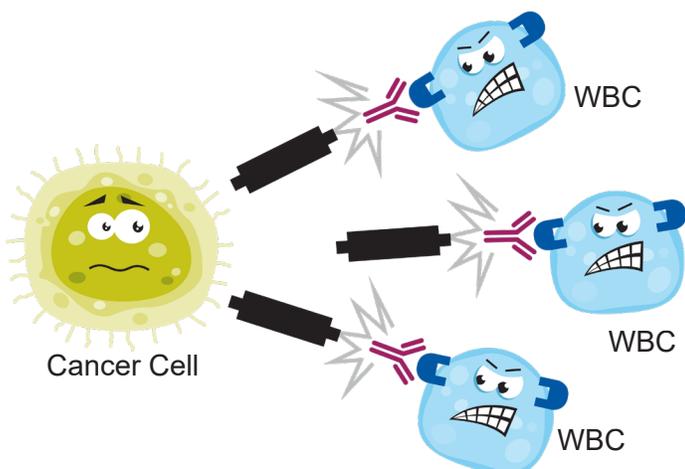
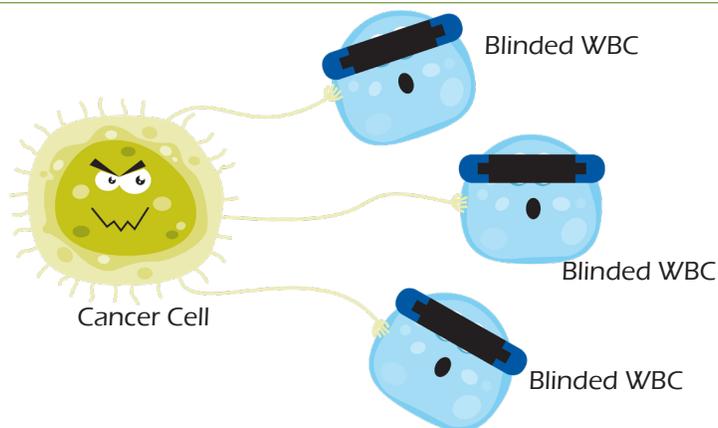


...and are activated to help destroy the cancer cell.

The WBCs find, fight and kill cells that are not normal or do not belong, like cancer.

Why didn't my immune system catch the cancer at the start?

Cancer cells sometimes act like they are part of the healthy body's system and hide in plain sight. WBCs do not recognize the cancer as an enemy, so the cancer cells are able to continue to grow.



How do checkpoint inhibitors work?

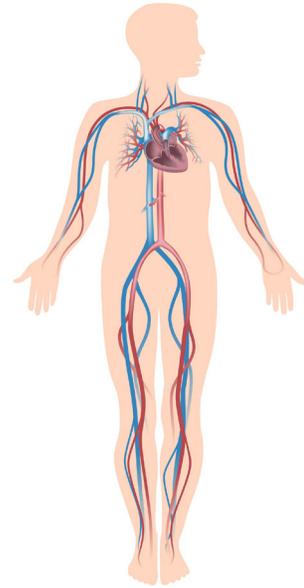
The checkpoint inhibitor turns on the immune system. The immune system is then able to remove the "blindfold" so that the WBCs can see and recognize the cancer cells and attack them.

Images ©2016 Free to Breathe, used with courtesy of Free to Breathe.

Things You May Want to Know About Your Treatment

The Basics of Your Treatment

You might hear the word 'systemic' treatment. Systemic treatment means that the treatment travels throughout your body in the bloodstream. Checkpoint inhibitors are one type of systemic treatment.



What are the goals of checkpoint inhibitor?

The goals are different for everyone and they can also change over time.

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
- Relieve or reduce symptoms the cancer may cause such as pain, or shortness of breath

How are treatment decisions made?

You and your healthcare team will talk about your treatment options together. The options depend on the type of cancer you have and where it is in your body. Research has shown us which treatments work best for different types of cancer. Other things we look at include your overall health, if you had treatment before, and what you would like to do.

Tip! **Terrie's Tip ~ cancer survivor:**
"Feel secure and cared for in the treatment plan that has been created with you."



Write down the goals you make with your oncologist here:

A graphic of a spiral-bound notebook with a red cover and white pages. The pages are lined and have a spiral binding on the left side. The notebook is positioned vertically and is intended for writing down goals.

Consenting to Treatment

Your Medical Oncologist may recommend checkpoint inhibitors as part of your cancer treatment, but **you need to decide if you want** to have a checkpoint inhibitor. To help make your decision, you need to know the:



- Goals for treatment
- Risks and benefits to getting the treatment
- Other possible treatment options other than a checkpoint inhibitor
- Possible outcomes if you do not have treatment



You can use the free AHS **My Care Conversations** app to prepare for your next appointment and to audio record conversations with your healthcare team. You can listen to your recordings at home and share with family or trusted friends.

Download it from the App Store or Google Play.



How will I get my checkpoint inhibitor treatment?

You will most likely get the treatment using an IV (intravenous) — the medication is put directly into a vein. Most patients get a temporary IV inserted and at the end of the treatment appointment, the IV is taken out.

You may get a central line. This is inserted into a vein and stays in until you no longer need treatment. Your doctor will prescribe this for you if needed.



Before the nurse starts your treatment, or even after treatment has started, you can say stop at any point if you have concerns.

If the nurse has any concerns, he or she may also stop the treatment. We want you to feel safe.

Common Questions

Where will I go to get my checkpoint inhibitor treatment?

Most patients go to their local cancer centre. A nurse will monitor you during your treatment. After your treatment is done, you should feel well enough to go back home or to work and continue with your day.

How long will my treatment appointments be?

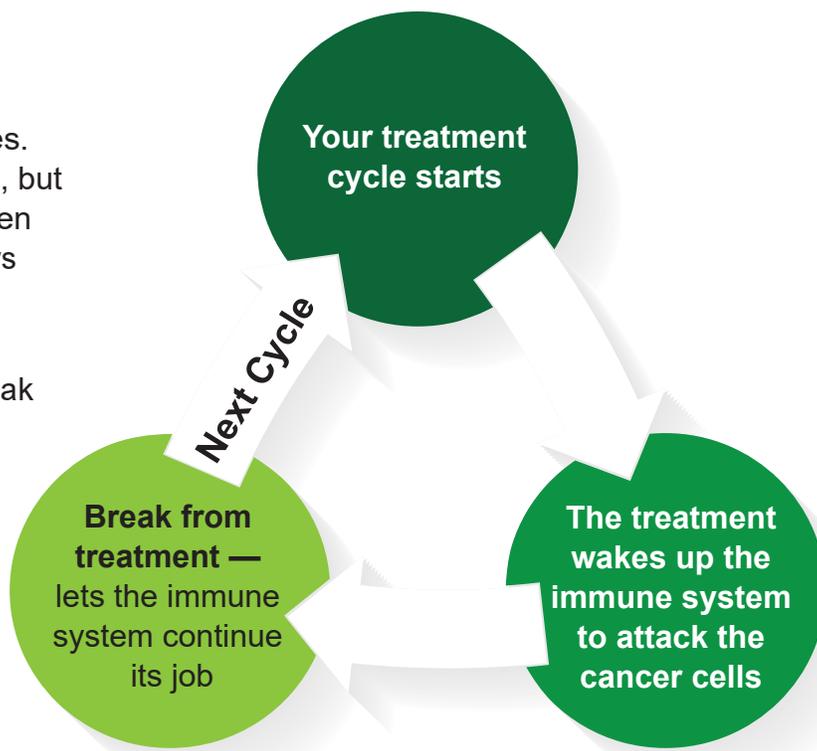


Some treatments only take a few minutes, while others can take a couple of hours. Your nurse will tell you how long your treatment will take. Preparing you for the treatment takes time, so you will be at the treatment appointment longer than just the amount of time it takes to give you the medication.

How often will I get my treatment?

In general, treatments are given in cycles. A cycle may be every 2, 3, 4 or 6 weeks, but this may vary. Your treatment will be given on the first day of each cycle. This allows the treatment to wake up your immune system and attack the cancer cells.

After each treatment, you will take a break for the rest of the cycle. Your immune system continues to attack the cancer cells before you move on to the next cycle. Your doctor will recommend the number of cycles you will need.



Is checkpoint inhibitor treatment painful?

There is usually no pain other than a needle prick at the start. Sometimes your vein may get irritated or discoloured.

If you feel any burning, redness or swelling while you get your treatment, tell your nurse right away.

Can I take other medications when I'm on checkpoint inhibitor treatment?

Tell your healthcare team (doctor, nurse or pharmacist) about any other pills, injections, or medicines you take, including vitamins, or herbal remedies. Some checkpoint inhibitors do not mix well with other medications and can become less effective in killing the cancer cells, or can make side effects worse.

Tell your healthcare team if you have any changes to your medications. (See pages [11-12](#))



After you leave your appointment, if you notice pain, redness or swelling in the arm that received the treatment, call the contact number your healthcare team gave you.



Pregnancy

If you think you are pregnant talk to your medical oncologist **before** you start your treatments.

We recommend that **both men and women use some form of birth control** before and during treatments since we do not yet know how checkpoint inhibitors affect an unborn baby.

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

B. In Treatment



Your Treatment Appointment

The Day Before Your Appointment

- Check your appointment slip for your appointment time and to see if there are any special instructions
- Pick up your anti-nausea medications or other pre-medications from your local pharmacy if needed
- Have your questions ready, arrange your ride, confirm who is coming with you, just in case you do not feel up to driving yourself home

Tip!

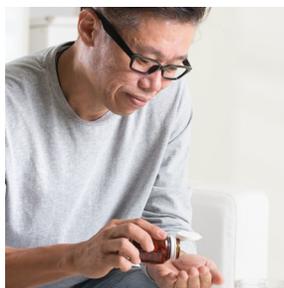
Drink 2-3 glasses of water **more than you normally do** the day before your appointment.

Drinking water helps “plump up” your veins making them easier to find, and may mean less pokes when you get your bloodwork done or an IV started.

The Day Of Your Appointment

Food:

- Eat a meal – your body needs nutrition and you will feel much better if you have something in your stomach



Medications:

- Take your regular medications as you normally would, unless you were told not to
- Take your anti-nausea medications or "pre-meds" as instructed (some may need to be taken during your appointment)
- Bring all your medications to your appointment

What to bring:

- Money or a way to pay for food or parking. You can also bring food to your appointment
- This booklet – the nurse can review questions you may have and go over some important points you need to be aware of
- Government identification and your healthcare card
- A book or electronic device (tablet/iPad) to help pass the time
- Questions you have written down to ask your healthcare team
- Bring all your medications to your appointment



Tip!

- Wear comfortable clothes
- Don't schedule other activities or appointments for the first treatment day

Can I bring family or friends to my appointment?

Friends and family are important but we have limited space. If you plan to bring more than 1 person, check with your healthcare team before your appointment to see if there are any limits with how many people you can bring.

Can I bring children?

Children 15 years of age or younger should not come for safety reasons. If you have difficulty getting childcare, call your cancer centre and ask to speak with a social worker to see what resources are available in your community.



For more information, check "Your Systemic Treatment Appointment" pamphlet that came with this booklet.

After Your Appointment

- Follow any special directions your healthcare team gave you
- Keep track of how you feel using your symptom tracker ([Keeping Track of Your Symptoms](#))
- Call your cancer centre if you have any questions or concerns

Information about Your Medications

Keep a Medication List

Carry a current list of your medications. Some medications do not work well with others and can affect your treatment. Your healthcare team can review your list to make sure this doesn't happen.

Let your healthcare team know if your medications change, including those prescribed outside of the cancer centre, such as from your family doctor.

Tip!

- Keep your list up to date
- Share your list with your healthcare providers at your appointments
- Know what time of day you take each medication, how much (dose) and how often
- Make sure you understand your medications and how to take them safely
- For medication lists and tools, go to: <https://myhealth.alberta.ca/Alberta/Pages/medicine-tracking-tools.aspx>



If you need refills on prescriptions **not related** to your cancer treatment (such as high blood pressure pills, or allergy medications), talk to your family doctor.

What do I put on my medication list?

Anything prescribed for you such as:

- Pills
- Liquids
- Patches
- Inhalers
- Eye/ear/nose drops
- Creams, lotions, and ointments
- Samples of medication

Anything you buy over the counter, such as:

- Pain killers
- Cold medications
- Laxatives
- Vitamins, minerals or supplements

Others:

- Homeopathic, natural, or herbal remedies
- Any recreational drugs, such as alcohol or marijuana (cannabis)

Flu Shot (Influenza Immunization)

Talk to your oncologist first if you:

- have not yet started treatment
- are on treatment now
- finished checkpoint inhibitor treatment in the past 6 months

Pharmacy Services at your Cancer Centre

The pharmacy at your cancer centre only provides cancer treatment medications. You need to pick up all other medications at your local pharmacy like those that treat or prevent nausea, hypersensitivity or allergic reactions, or pain medications.

Remember to tell the pharmacist and healthcare team if you have any allergies to medications. We also want to know what kind of reaction you had — was it a rash, or did you have difficulty breathing.



- Do not discontinue or change the dose of any medication unless you talk with your doctor.
- Take only the medications that have been prescribed or approved for you.
- If you have any questions or concerns, about any medications, talk to your healthcare team or a pharmacist.
- Tell your healthcare team if you have any allergies to medications.



You can find information and resources to help you learn more.
<https://myhealth.alberta.ca/Alberta/Pages/know-your-medications.aspx>



C.

Possible Side Effects



Are there side effects from checkpoint inhibitors?

There are possible side effects. Your healthcare team will talk to you about them, but it does not mean you will have all or even any of them. Everyone is different. Different checkpoint inhibitor drugs may have different side effects.

How does checkpoint inhibitor treatment cause side effects?

When checkpoint inhibitors wake up the body's immune system, the immune system may become over activated and also attack some of the body's normal cells, which can cause side effects. These are called **immune-related** side effects.

If you notice something different with your body, or how you feel, tell your healthcare team right away. They can help you manage or treat the side effects.

When will the side effects happen?

Side effects can happen anytime during treatment and may even happen after you stop treatment. You should know what side effects are possible so you can recognize them. Always talk to your healthcare team if you notice anything different.

What should I tell an emergency room doctor or family doctor about my treatment?

If you ever have to go to the emergency room, **bring your emergency letter with you to give the healthcare staff.**

This letter lets the healthcare staff know they should contact your medical oncologist to find out how to manage your side effects. Checkpoint inhibitors are special medications and medical oncologists are experts in knowing how to manage them.

You should also bring your letter when you see your family doctor. **If your doctor prescribes you new medications, such as antibiotics, tell your cancer team** — they need to make sure they will not interfere with your treatment.

Side effects are different for everybody. You may get a lot of side effects, or just a few. Sometimes the side effects may be severe, or you might not notice them at all.

Tip!

Carry your emergency letter with you, or take a picture of it with your phone so you always have it with you.

This side effects section is split up into 2 categories:

1. Possible side effects from checkpoint inhibitors (pages 14-17)
2. Other general side effects — these are side effects that are common for people with cancer. They may be caused by the treatment, or some may be caused by the actual cancer itself. (pages 18-26)

Possible Side Effects of Checkpoint Inhibitors

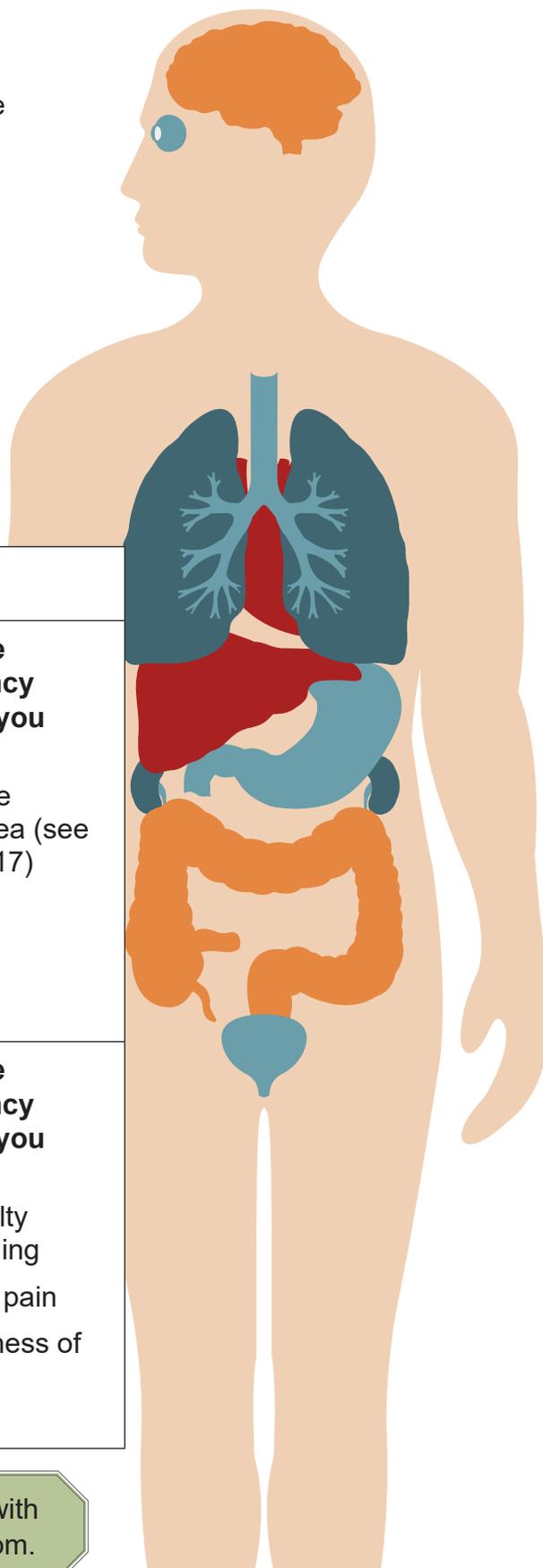
What side effects can I expect?

The types of side effects and how severe they are will depend on which checkpoint inhibitor you receive, and how your body responds to the treatment. Your healthcare team will review the side effects with you and what you can do about them. It's important to remember that these are **possible side effects only**.

Immune-Related Side Effects



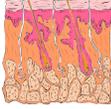
Immune-related side effects often do not get better on their own. Make sure you tell your healthcare team if you have any of the side effects listed in the table below or on the next page. They can help you get the treatment you need, so do not try to manage these yourself.

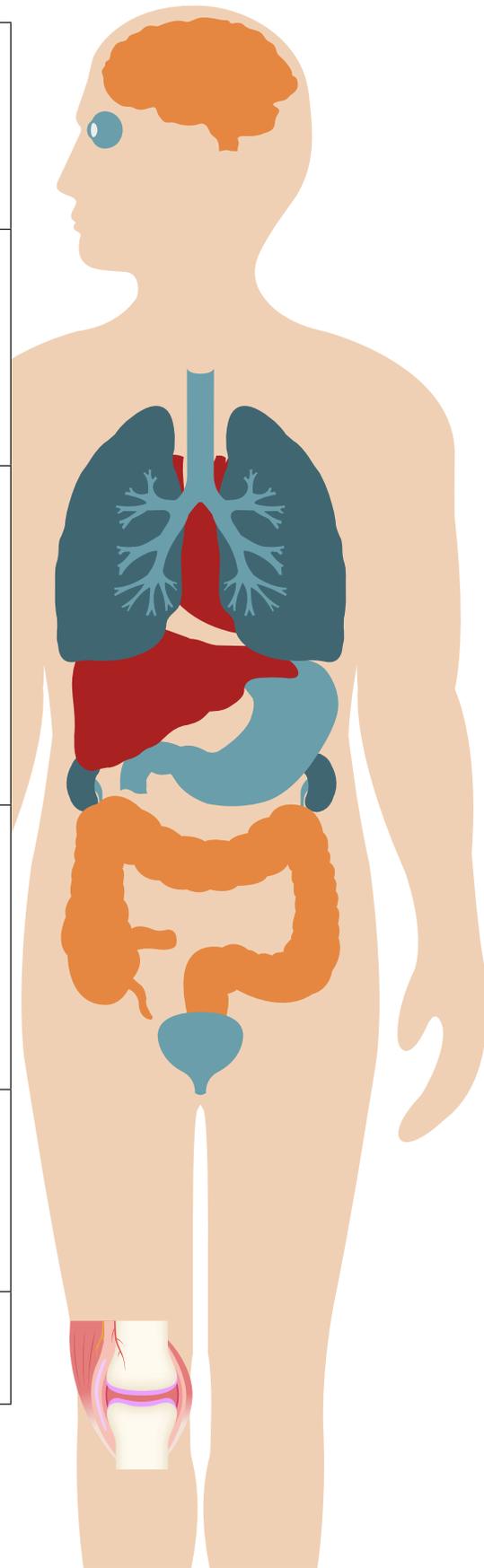


Area affected:	What to watch for:	
Stomach and Intestines 	Talk to your healthcare team if you have: <ul style="list-style-type: none"> <input type="checkbox"/> Stomach pain <input type="checkbox"/> Cramps <input type="checkbox"/> Burning feeling in your stomach <input type="checkbox"/> Heartburn <input type="checkbox"/> Indigestion <input type="checkbox"/> Nausea 	Go to the Emergency Room if you have: <ul style="list-style-type: none"> <input type="checkbox"/> Severe diarrhea (see page 17)
Lungs 	Talk to your healthcare team if you have a: <ul style="list-style-type: none"> <input type="checkbox"/> Cough with or without mucous <input type="checkbox"/> Cough that is different than usual <input type="checkbox"/> Cough with or without fever 	Go to the Emergency Room if you have: <ul style="list-style-type: none"> <input type="checkbox"/> Difficulty breathing <input type="checkbox"/> Chest pain <input type="checkbox"/> Shortness of breath



Remember to take your emergency letter with you if you need to go to the emergency room.

<p>Skin</p> 	<p>Talk to your healthcare team if you have:</p> <p><input type="checkbox"/> Rash <input type="checkbox"/> Hives</p> <p><input type="checkbox"/> Blisters <input type="checkbox"/> Itchiness</p>
<p>Muscles, joints and nerves</p> 	<p>Talk to your healthcare team if you have:</p> <p><input type="checkbox"/> Aches and pains <input type="checkbox"/> Numbness or tingling in the hands or feet</p> <p><input type="checkbox"/> Severe muscle weakness/fatigue</p>
<p>Liver</p> 	<p><input type="checkbox"/> Side effects can happen to the liver, but usually you will not notice them. Your healthcare team will use blood tests to make sure there is no change in your liver function.</p> <p>Talk to your healthcare team if your:</p> <p><input type="checkbox"/> Eyes or skin turn yellow</p> <p><input type="checkbox"/> Stools (poop) become lighter in colour</p>
<p>Eyes</p> 	<p>Talk to your healthcare team if you have:</p> <p><input type="checkbox"/> Burning/pain <input type="checkbox"/> Reddened eyes</p> <p><input type="checkbox"/> Blurred vision <input type="checkbox"/> Discharge</p> <p><input type="checkbox"/> Irritated eyes <input type="checkbox"/> Itchiness</p> <p><input type="checkbox"/> Sensitivity to light</p>
<p>Kidneys</p> 	<p><input type="checkbox"/> Side effects can happen to the kidneys, but usually you will not notice them. Your healthcare team will use blood tests to make sure there is no change in your kidney function.</p>
<p>Hormones</p>	<p><input type="checkbox"/> See page 16 for more information on hormones and the side effects</p>



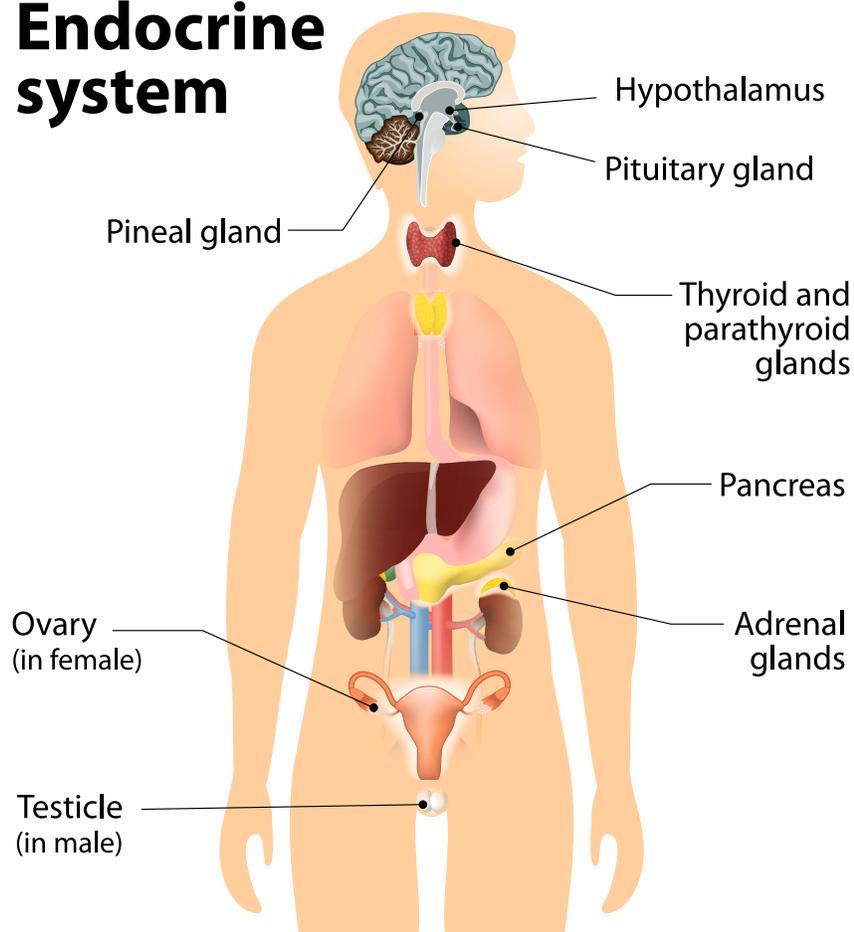
You know your body best, and you can tell when you're feeling well or unwell.

Tell your healthcare team right away if you have any of these side effects so they can help you with them. You might need medication to help treat them.

Hormones

Hormones are made by the endocrine glands in our bodies. Hormones are chemical messengers that travel in the body and help control how cells and organs work. They help the body work the way it's supposed to.

Endocrine system



Checkpoint inhibitors can affect these glands in the endocrine system, and cause side effects. These can include:

- Fever (page 17)
- Chills
- Headache — new or will not go away
- Change in your appetite (page 18)
- Cracked or dry skin/hair
- Change in your blood sugars
- Nausea and vomiting
- Fatigue or weakness (page 20)
- Weight change (gain or loss)
- Change in your mood or behaviour
- Trouble sleeping (page 26)
- Change in blood pressure

Sometimes these side effects can be caused by other things, so talk to your healthcare team if you experience any.



Go to the Emergency Room if you have difficulty seeing out of the sides of your eyes (loss of peripheral vision)



Fever

Fever may be a normal response to treatment with a checkpoint inhibitor.

If you have a mild fever, use acetaminophen such as Tylenol® to help reduce your symptoms.



Call the contact number your healthcare team gave you if your temperature is 38.9°C/102°F or higher with any of the following:

- It lasts longer than 24 hours
- You feel unwell
- You have other symptoms such as cough, shortness of breath, pain, dizziness, nausea or diarrhea

Diarrhea

Diarrhea is an increase of 2 to 3 watery or loose stools (poops) above your normal number of bowel movements.

You may have cramps, pain, or feel bloated. Diarrhea is serious because you can lose a lot of fluid and nutrients, which can cause you to become dehydrated and tired.

If diarrhea goes on long enough, or is severe enough, it can damage your intestines or kidneys.

It's very important to **call your cancer centre** if:

- your diarrhea does not go away after more than 24 hours (1 day)
- you notice blood in the diarrhea or bleeding in your rectal area
- you have dark, tarry stools
- you have severe cramps
- you cannot drink enough fluids to replace the fluid lost in your diarrhea

Go to the Emergency Room if your diarrhea is severe — **4 or more times a day**



Other General Side Effects

Appetite Changes

Some medications can cause you to lose your appetite.

A poor appetite that lasts longer than a few days can lead to a loss of weight, muscle and strength. You also won't have the nutrition your body needs to heal and repair itself to fight the cancer.

Things that can cause you to lose your appetite:

- Changes to how your body breaks down your food and uses it for energy
- Advanced cancer
- A buildup of fluid in the abdomen (ascites) that may make you feel full
- Other medications, such as medications to treat pain



If you have a poor appetite and are eating only small amounts or not eating at all, talk to your healthcare team or a dietitian.

What can I do to maintain or improve my appetite?



- Try new foods and drinks to find flavours that taste good to you.
- Make a list of foods you like. Eat them often, even if you eat the same foods over and over for awhile.
- Choose soft foods that need less chewing.
- Don't eat foods that taste bad to you.



- If your mouth is dry, try to increase the amount of fluids you drink to 8 cups (2 litres) each day. This will help keep your mouth moist and improve your appetite.
- If you have been told to limit your fluids, speak with your doctor or dietitian.



- Brush your teeth and tongue with a soft toothbrush before and after each meal.
- Wait 10-15 minutes after you brush to eat — this will help "wake up" your taste-buds.



- Try not to use tobacco products — they can make food taste bad (page 35).



Blood Clots

Blood clots are also called Venous Thromboembolism (VTE). VTE is a blood clot that forms in the veins of the body or in the lungs. People with cancer are 5-7 times more likely to develop a clot than someone who does not have cancer.

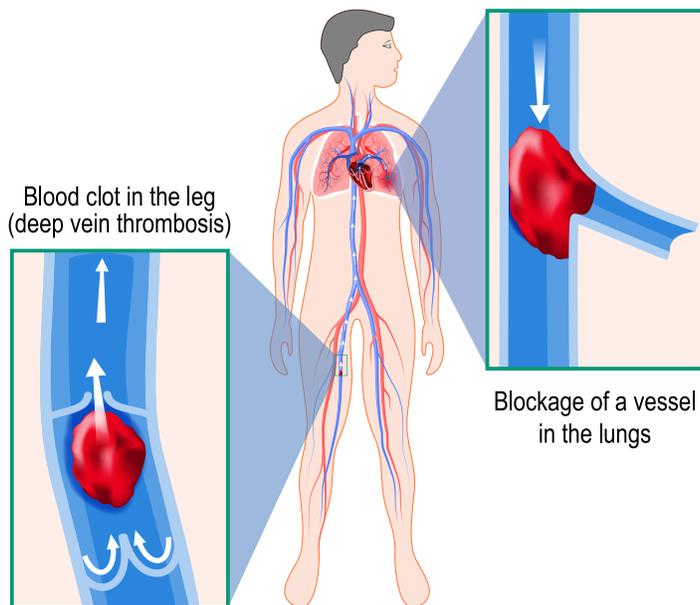
The most common vein blood clots are:

Deep Vein Thrombosis (DVT):

- A blood clot forms in a vein of the leg or pelvis
- It may partially or totally block the flow of blood

Pulmonary Embolism (PE):

- A blood clot forms in the lungs
Or
- A blood clot forms somewhere else in the body. It then travels through the bloodstream to the lungs. Once it gets to the lungs, it can get stuck there and cut off the blood supply to the lungs



Get more tips from the booklet [Blood Clots and Cancer](#) at your cancer centre or online at www.cancercarealberta.ca

What are the signs and symptoms of a clot?

Deep Vein Thrombosis (DVT)

- Pain or tenderness in the calf, behind the knee, along the inner thigh to groin
- Swelling
- A change in the colour of your skin (a blue, purple or red colour) in the area around the site of the clot
- The area feels warm to touch

Pulmonary Embolism (PE)

- Shortness of breath or trouble breathing
- Chest pain or upper back pain, especially when you breathe
- Coughing up blood
- Unexpected rapid heart rate
- Dizziness or feeling faint



If you have any of these symptoms, go to your nearest emergency centre right away.

Fatigue

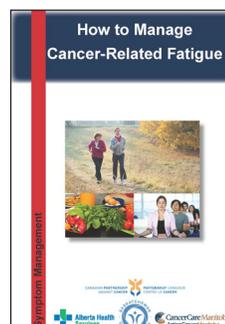
Fatigue (or tiredness) is a very common side effect related to treatment and cancer. It is best treated with regular exercise and good nutrition.



For more information on how to manage cancer-related fatigue, visit bit.ly/fatigue-videos

Fatigue may make you feel:

- worn out, tired, sleepy, no energy
- can't concentrate or think
- lack of interest in doing anything with friends or family
- no interest in sex or being intimate with your partner
- depressed, disconnected or not interested in anything
- short of breath



Get more tips at from the booklet [How to Manage Cancer-Related Fatigue](#) at your cancer centre or online at www.cancercarealberta.ca

What can cause fatigue?

- weight loss
- stress
- cancer treatment
- cancer
- poor nutrition or getting enough calories and protein
- changes in your daily schedule or interrupted sleep schedule

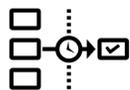
How can I manage my fatigue?



- Stay as active as possible before and during treatment. Exercise may be a simple walk once or twice daily. See Physical Activity (page 34) for more ideas



- Set a goal of 8 hours night time sleep. A good sleep is more likely when you go to bed at the same time every night and follow a routine.



- Pace yourself day by day. Prioritize and plan your activities according to how you feel that day.
- You may not be able to do everything on your list so decide what's most important for you and ask for help from others to complete the remaining tasks.



- Eat smaller, more frequent meals and snacks
- Eat a balanced diet, with protein rich foods
- Ask to speak to a registered dietitian to learn how nutrition can help manage fatigue

Tip!

Christine's Tip ~ cancer survivor:

"I booked appointments with myself to go for walks. This really helped, especially when I was exhausted and knew it was the only thing that would help get my energy back. I couldn't break a date with myself!"



Fertility

Fertility is the ability to get someone pregnant or to get pregnant and carry a child to a healthy birth. Cancer and cancer treatment can sometimes damage the reproductive organs such as the ovaries and testicles. These changes can have short-term or long-term effects on your fertility.

Cancer treatment can cause changes to the reproductive organs like:

- decreased sperm quality, number, and motility
- irregular periods, or it may stop women from having periods
- early menopause

Tip!

Before you start your treatment, check with your healthcare team to find out what your options are for preserving your fertility.

Talk to your doctor or visit:

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



Questions to get the conversation started:

- How will my cancer treatments affect my fertility?
- What are my fertility preservation options?
- How will I know if I am fertile after treatment?
- If I don't preserve my fertility before treatments, what are my options after treatment?
- Do I have a type of cancer that can be passed on to my children?
- After my cancer treatments finish, how long do I need to wait before becoming pregnant or fathering a child?





Pain

Cancer can sometimes cause pain or discomfort. You may feel pain all of the time or only some of the time. Only you know how much pain you feel and how it affects you. Getting relief from your pain is important.

Treating your pain will help you:

- Sleep and eat better
- Enjoy time with family and friends
- Do your work and hobbies



You do not have to accept uncontrolled pain as a normal part of living with cancer. Tell your healthcare team if you have pain so they can help you manage it properly.

Pain is different for everyone but the symptoms are similar depending on where it is coming from. If you can tell your healthcare team how it feels, it will help us figure out how to treat it quicker.

Bone pain — a deep throbbing pain that can be sharp at times. It may get worse when you move around.

Visceral pain — might feel like a dull, deep squeezing pain. It is caused from damage to the organs inside your body. It can be hard to tell exactly where the pain is coming from.

Neuropathic pain — may feel like a burning, shooting, piercing, stabbing or like an electric current. It might feel like pins and needles or tingling. It is caused from damage to your nerves. It can hurt when things like clothing, water or wind touch your skin.

What causes cancer-related pain?

- cancer tumour or symptom
- cancer treatments
- other symptoms like constipation or nausea
- emotional, social and spiritual impact of cancer
- stress or anxiety
- medical procedures and tests
- other health factors
- medications

Tip!

Some people think they should save their pain medication in case the pain gets worse later. Pain should be treated early, so make sure you take the medication as prescribed.

Your doctor can change your dose of pain medication, or the type of medication you take if you need.

Continued on next page



What can I do to manage my pain?



- Take your medications as prescribed. Sometimes it may take more than 1 type of medication to help decrease and control your pain.
- Talk to your pharmacist if you have a hard time remembering what medications to take and when — they may have helpful suggestions.
- Keep track of when you take your pain medications — this will help to see if the dose is the right amount for you or if it needs to change.



- Be active and exercise. Even a small amount of exercise, such as walking up and down your hallway, will help with your pain.



- Find support. It is normal to feel upset and frustrated when you are in pain. You can find support in your community, with family and friends, and through your healthcare team.



- Relaxing activities and managing stress may help to control your pain.



- There may be other treatments to help you but it is important to speak with your healthcare team before you try them.

Is it normal to feel nervous about taking pain medications?

Some people do not take pain medications because they worry about getting addicted. If you take your medication as your doctor prescribed, you should not worry. Addiction happens when a person takes medications for reasons other than pain.

Side effects of pain medications:

- Nausea and vomiting
- Drowsiness
- Constipation

A spiral-bound notebook with a red cover and lined pages, positioned vertically on the right side of the page. The notebook is open to a blank page with horizontal lines, ready for writing.



Problems with Memory

It is common for people with cancer to have problems remembering things, or taking a longer time to understand information. This is called "brain fog". Often it's temporary, but sometimes it can last months to years after treatment is done.

Things that can sometimes cause brain fog are:

- Medications
- Dehydration – not drinking enough fluids
- Anxiety
- Fatigue
- Depression
- Impaired sleep

Signs and symptoms of brain fog are:

Difficulty:

- focusing, concentrating, and paying attention
- remembering names, phone numbers, or words
- understanding information
- understanding directions
- problem solving like doing simple math or balancing a check book

Feeling:

- like your thoughts are jumbled and words are difficult to find when you are speaking
- confused



If you notice any of these symptoms, please tell your healthcare team.

What can I do to help with brain fog?



- Write things down in a journal
- Make lists



- Complete a task before you start another one



- Keep a calendar of when you have appointments and important events



- Get adequate sleep



- Drink enough fluids and eat a healthy diet (page 32)



- Physical Activity (page 33)



- Put things back in the same spot you always do, for example keep car keys in the same drawer



Sexuality and Intimacy

Sexual health affects people of all ages, genders, sexual orientations, cultures and beliefs. It can be an important part of your personal identity. Cancer and the treatments can alter your sexuality and the intimacy you have with your partner in different ways. Sexuality can mean something different for each person and can change over time.

What are some common concerns for cancer patients?

- Vaginal symptoms — pain with sexual activity, vaginal bleeding, dryness or discomfort
- Erectile dysfunction — difficulty getting or maintaining a firm erection
- Hormonal changes — hot flashes, changes in body, fatigue
- Body image — changes in how you feel or think about your body
- Loss of libido — less interest in sex, loss of sexual fantasy or thoughts
- Difficulty with arousal or orgasm — feeling like your body is not responding sexually like it used to
- Relationship changes — changes in roles, not connecting with your partner
- Anxiety or fear related to sexual activity, loss of sexual confidence, uncertainty about being sexual

Is it safe to be sexually active?

Yes, but you or your partner should use birth control during treatment to avoid pregnancy. Your healthcare team may give you more information.

Skin Changes

Skin reactions can happen anywhere on the body, and may cover small or large areas of the body. The skin-related reactions to checkpoint inhibitors may include:

- Rash
- Skin that feels itchy, painful, or tight
- Skin that develops blisters
- Skin that is peeling or cracked
- Patches of skin that have become red or discoloured
- Patches of purple spots on the skin
- Patchy areas of hair loss



It's very important to call your cancer centre if:

- you develop a rash with blisters
- the skin is peeling off

Go to the Emergency Room if you cannot speak to someone at your cancer centre.

Where can I get help?

Sexual Health Booklet Series:

 Pick them up at your cancer centre.

 Or go online www.ahs.ca/cancertreatment

- » Managing Side Effects
- » Sexual Health

Ask your healthcare team for a referral to the **Oncology and Sexuality, Intimacy & Survivorship (OASIS) Program**



Sleep Pattern Changes

Getting enough sleep helps improve your health. It can help with things like healing, digestion, emotional well-being, and brain function like memory and problem solving.

What is a sleep pattern change?

- Difficulty falling asleep
- Difficulty staying asleep
- Sleeping more than usual but not waking up feeling rested
- Waking up earlier than you normally do

Why does this happen?

There are many things that can cause changes to your sleep, such as:

- The cancer itself
- Insomnia (where you can't seem to fall asleep, or stay asleep)
- Side effects from the cancer treatment, such as diarrhea, or nausea
- Pain (see pages [22-23](#))
- Fatigue (see page [20](#))
- Depression (see page [28](#))
- Mood

What can I do to help improve my sleep pattern?



- Take your medications as prescribed to help manage pain or nausea and vomiting



- If you feel depressed let your healthcare team know. They can refer you to a psychologist.
- Speaking with a psychologist can give you a chance to talk about your concerns in a safe and caring environment ([page 27](#))



- If you nap during the day, try and nap between 1 and 3 pm and only for 30 minutes.
- Try to nap on the couch or in a recliner. Save the bed for sleeping at night



- Turn off all electronic devices 1 hour before you fall asleep — this includes televisions, cell phones, and laptops



- Exercise, even if it is just a short walk ([page 33](#))



- Create a calm, quiet environment to sleep in



D.

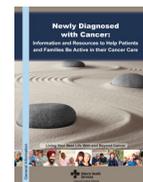
Living Your Best



Emotional Self Care and Awareness

Difficult emotions often arise during cancer and its treatments. Psychosocial Oncology experts can offer counselling to patients and family members to help reduce emotional distress and explore coping techniques. They help with things such as communication, stress, coping with treatment side effects, mood changes, quality of life, body image or loneliness. Patients and family members are welcome to call and ask for an appointment or information.

For more information or for contact details look in the **Newly Diagnosed With Cancer Book**



Anxiety

What is anxiety?

Anxiety is a feeling of worry, fear, or being nervous and is a normal feeling for patients and families to have when going through a cancer diagnosis.

Tip!

People who learn about their cancer and treatment options may feel more in control and have less anxiety.

Be ready for your appointments with a written list of questions, and bring a support person if you can.

What are signs and symptoms of anxiety?

- Tense muscles
- Feeling restless, worried, or not able to relax
- Trouble sleeping
- Feeling moody or stressed

Some people have strong anxiety which can cause anxiety attacks. You may feel:

- Feelings of doom
- Dizziness and nausea
- Shortness of breath
- Chest pains
- Heart palpitations (your heart feels like it is fluttering or pounding)

What causes cancer-related anxiety?

- Finding out you have cancer
- Worrying about your family, especially if you have kids
- Waiting for test results
- Feeling like you have no control over your life
- Dealing with an anxiety disorder before you had cancer
- Worrying about money, your job and other practical things
- Medications, like steroids or some anti-nausea medications
- Feeling badly from side effects like nausea and pain
- Fear of cancer coming back, suffering, or dying
- Depression
- Having new symptoms that scare you

Depression

Depression is different from sadness. It lasts longer and has more symptoms. Depression can make it difficult to live your life in a way that is healthy, enjoyable and meaningful.

Some people experience depression before, during or after treatment while others do not experience depression at all. It can depend on your:

- type of cancer
- stage of disease
- symptoms and how severe they are
- support systems and how good they are
- history of mental health issues



If you are thinking of suicide or harming yourself, call 911 or go to your nearest emergency department right away.

What causes cancer-related depression?

- Learning you have cancer or your cancer has returned
- News your cancer cannot be cured
- Feeling a loss of what your life was like before cancer
- Depression or addiction before your cancer diagnosis
- Feeling isolated
- Some chemotherapy medications or hormonal treatments
- Pain or fatigue
- Side effects like hair loss, nausea, or sexual problems
- Changes in your body, like losing a breast



If you feel depressed, let your healthcare team know. With professional counselling, you can learn about different ways to help you cope.

If your depression does not get better or gets worse, you may need medications to feel better.



www.ahs.ca/cancersupportivecare» Psychosocial Oncology

Continued on next page



What are the symptoms of depression?

People can have both physical and emotional or mental symptoms when they have depression. Some of the symptoms are:

Physical symptoms:	Emotional and mental symptoms:
<ul style="list-style-type: none"> • Low energy • Feeling sluggish or restless and agitated • Sleeping and eating more than before 	<ul style="list-style-type: none"> • Feeling hopeless or worthless • Not enjoying the things you used to enjoy • Feeling of guilt or regret • Wanting to die • Worsened anxiety • Have trouble thinking or remembering things

What can I do to help my anxiety or depression?

Find support:



- Talk to someone you trust and who is a good listener — friends, family or co-workers.
- Talk to a social worker about support programs at your cancer centre and in your community.
- Get professional help. Professional counsellors can help you learn new ways to manage your anxiety and worry.



- Focus on things that make you feel better.
- Think about the positive parts of your life and the things you can control.
- Spend time with people who make you laugh and avoid those who are negative.



- Try relaxation activities like listening to music, yoga, or deep breathing.



- Get a good sleep — this can give you more energy and help you feel better emotionally.



- Exercise and take care of your body. It's a good way to help you feel better and improve your mood.



- Some people find writing in a journal or expressing their feelings through art can help.



- Try to limit or avoid alcohol because it can lower your mood.

Maintaining and Improving Quality of Life — What Palliative Care Can Offer

Palliative care is often misunderstood and can be seen as a negative or scary thing. In fact, it can provide many benefits to both patients and families.

Palliative care can be:

- an added layer of support for you and your family
- appropriate at any age and at any stage of cancer
- provided along with treatment for the cancer or by itself
- needed to help with a one time issue, needed from time to time, or needed as a longterm form of support

What can palliative care do?

Palliative care can help patients and families live life to the fullest.

Palliative care:



Who provides palliative care?

Your current care team can provide some palliative care.

There are also specialized palliative care teams (doctors, nurses, pharmacists, social workers and other professionals) who work together with you, your cancer doctor and your family doctor to focus on issues important to you. This team works with you to make care plans based on your values, preferences and wishes.

How do 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.

For more information:

- Talk to your healthcare team
- Find out more about palliative care in Alberta or find programs and services in your community - <https://myhealth.alberta.ca/palliative-care> (ALBERTA)
- Check out www.virtualhospice.ca and livingmyculture.ca (CANADA)



Improving Your Health and Lifestyle

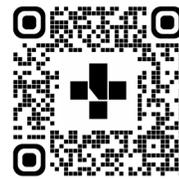
Taking care of yourself is important during treatment. Listen to what your body is telling you and don't push it – do what you can for that day. Every day is a new day and how you feel, physically and emotionally, depends on the day.

Here are some tips to help you achieve living your best through treatment:

- Carry on with everyday activities if you feel up to it
- Ask for help or accept it when it's offered
- Explore what works best for you – not everything is going to work for everybody
- Surround yourself with people who can help and support you



For more information about living well during treatment, visit: cancercarealberta.ca



Alcohol

With some drugs, you may need to limit the amount of alcohol you drink or avoid it altogether. Ask your clinic nurse, doctor, or pharmacist.

If you find you have questions or need help, let your healthcare team know. There are resources available to support you and your loved ones during your cancer treatment.

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.
- Dilute alcoholic drinks, or choose low-calorie or low-alcohol alternatives.
- Don't drink alcohol when you are thirsty. Have a glass of water or a soft drink first.
- Keep at least a few days each week alcohol free.
- Avoid salty snacks such as potato chips or nuts while drinking alcohol.
- Drink alcoholic beverages slowly and space out your drinks.
- Eat before and while you are drinking.
- Don't use alcohol to cope with stress.

Tip!

Nutrition

Nutrition will improve your treatment outcomes and quality of life. Eat a healthy diet to give your body the energy to heal and to do your everyday activities.

Choose a variety of foods:

- Vegetables and fruits
- Whole grain foods
- Protein foods

Eat foods with protein to help you:

- meet your protein needs
- maintain strength
- keep your immune system healthy

Eat enough so you don't lose weight

If your appetite is poor, it may help to eat smaller meals more often, and eat snacks between meals. It may also help to eat foods that are higher in energy (calories).

Higher energy foods with protein:



beef, pork, poultry, fish, and eggs



milk, cheese, and yogurt



beans, lentils, nuts, nut butters, seeds and tofu



protein powders and nutrition supplement drinks

Higher energy foods without protein:



avocado, dried fruit, granola, cream and wheat germ



margarine, butter, vegetable oil, salad dressing, mayonnaise, creamy sauces, gravy, and coconut milk



sugar, syrup, jam, candy, and desserts

Wash your vegetables and fruits with water before you eat them

This helps remove any germs that are not visible. Proper handling, storage, and cooking of meat is also important. Raw meat can have bacteria that can make you very sick if you don't cook it or store it properly. Keep raw meat and fresh fruit and vegetables separate.



If you want more information on what to eat, drink, or both, ask your healthcare team to speak with a dietitian. A dietitian can give you guidance and tips for healthy eating during your treatment.

If you have lost weight, or have no appetite, talk to your dietitian or nurse.



Physical Activity

Regular exercise before and during treatment has been shown to reduce how severe the side effects can be.

Exercise and physical activity while receiving Checkpoint Inhibitors can help you:

- reduce fatigue and improve energy levels
- reduce your risk for blood clots
- reduce nausea
- boost your immune system
- lower your risk for falling by keeping you stronger
- improve your mood and help you feel better as treatment progresses



Studies show that exercise helps patients feel better — even something as short as a 10-15 minute walk.



Always talk to your healthcare team before you start a new exercise program.



Exercise is safe and good for you. If you have other health issues, check with your healthcare team before you start a new exercise program. For example, if you have trouble walking, it might help to have a referral to occupational therapy or physiotherapy.

Tips on how to keep active:

- Choose more vigorous exercise/physical activity on days when you have more energy and lighter exercise when you have less energy.
- Find an exercise video to do with a family member or on your own.
- Create stations around your house: do heel raises at the bathroom sink; put cans of soup on your coffee table and use them as weights while you watch TV; straighten your knee, one leg at a time when sitting in a chair before meals. Some exercise is better than none — use your imagination.
- When your friends or family ask what they can do to help, ask them to make a walking date with you. Good company helps keep us motivated to stay active. In the winter, you can walk in the mall.

Integrative and Complementary Therapies

Complementary therapies include different healing approaches not considered to be standard medical treatments. Sometimes they are used alongside or as a "complement to" mainstream medical care.

- **Standard medical treatments** are scientifically tested and researched and include treatments such as radiation, surgery, and systemic treatment like Checkpoint Inhibitors. These treatments are used by doctors to treat people with cancer.
- **Complementary medicine** is used along with standard medical treatments. It is meant to help relieve symptoms or side effects, or boost emotional or physical health.

It is your choice to use or not to use these therapies. But it's important to **talk to your oncologist if you are thinking about using complementary therapy or if you have any questions or problems.** Check with your pharmacist or registered dietitian to see if there are possible interactions with medications or supplements.



Does my healthcare team need to know if I am using or plan to use complementary therapies?

Yes. Tell your doctor or nurse about anything you are taking or planning to take.

Some complementary therapies may make your treatment less effective. It's always best to talk to your healthcare team before you start anything.

Complementary therapy can include things like:

- | | |
|-------------------------------|-------------------|
| • pills | • injections |
| • vitamins | • herbal remedies |
| • massage | • acupuncture |
| • hyperbaric oxygen treatment | • cannabis |

Are there natural health products I can take during treatment?

- You can take a regular strength multiple vitamin and mineral supplement. Choose a brand that is made for your age group. The supplement should have small doses of a wide variety of nutrients (high doses are not recommended).
- We recommend that you do not use other natural health products for **1 month after** you finish your treatments, and when possible, for **1 month before** you start treatment.

To find out more, visit:

CAMEO website: cameoprogram.org

Canadian Cancer Society's website:

www.bit.ly/CCS-complementary-and-alternative-therapies



Tobacco Products

We know stopping the use of tobacco can be difficult and often takes several tries. By stopping your tobacco use after a cancer diagnosis, you can improve your health and body's response to treatment, whether it's surgery, radiation or checkpoint inhibitor.

Studies show many important benefits of quitting the use of tobacco after a cancer diagnosis, including:

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

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

Alberta Quits

Operated by experts, Alberta Quits gives:

- Support from trained cessation 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 and motivational text messages

Tip!

Personalize your online dashboard and build your own plan to quit. It's free to use, and research shows that getting help makes you twice as likely to be successful at quitting.

 1-866-710-7848  www.albertaquits.ca  www.healthiertogether.ca

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

Some of the symptom management information was adapted with permission from Cancer Care Ontario.

Cancer Care Alberta

Leading care through compassion, courage, learning and discovery

Visit us online at www.cancercarealberta.ca

