Checkpoint Inhibitor and Chemotherapy:

Information for Patients and Families





Please bring this booklet to the class and your appointments.

Treatment — Systemic

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 and chemotherapy treatments are and how they are 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 may be able to attend a class at your cancer centre before you start or during your treatment. Ask when the next 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

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/

My Plan:



I will have _____ cycles.



Write phone numbers or notes here.





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

You do not have to

pick and choose the

sections you want to know more about

when you need them.

read the whole book -



Check out the **Newly Diagnosed With** Cancer Book if you do not already have it.

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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Just Diagnosed

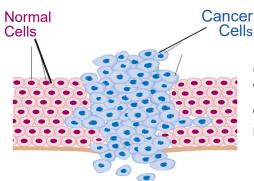


It's important to understand what cancer is, so you can understand your treatment better.

What is Cancer?

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

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:

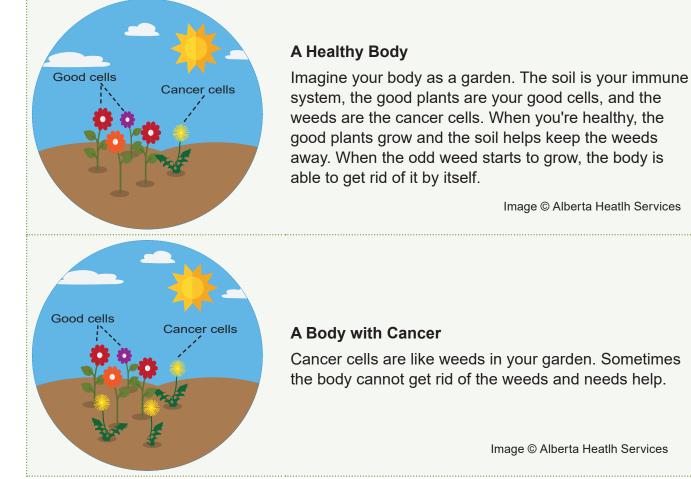


Image © Alberta Heatlh Services

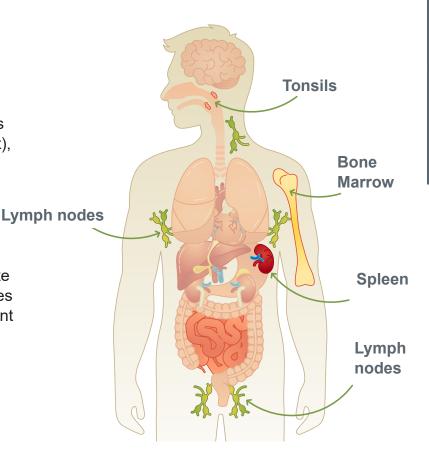
The Immune System

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.

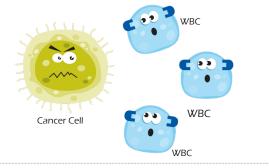


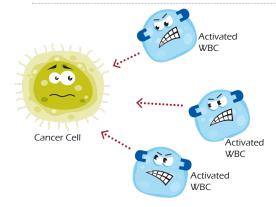
The memory — remembers what the cancer cells look like so if they show up again, the attack is quicker.

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

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.

Cancer Cell

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.

Things You May Want to Know About Your Treatment

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

Systemic treatment means that the treatment travels throughout your body in the bloodstream with the aim of destroying cancer cells.

You will be getting a combination of 2 different systemic treatments — **chemotherapy** and **checkpoint inhibitors**.



Blinded WBC

Blinded WBC

Blinded WBC

What is chemotherapy?

Chemotherapy treatment can be made up of a single drug, or a combination of drugs. It's used to destroy cancer cells or to prevent new cancer cells. It is also known as "chemo."

How does chemotherapy work?

Chemotherapy finds the cancer cells and attacks them, or keeps them from dividing and making more.

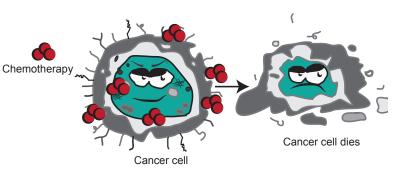
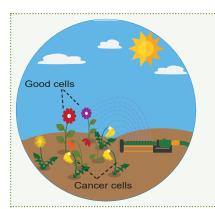


Image © Alberta Heatlh Services



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.

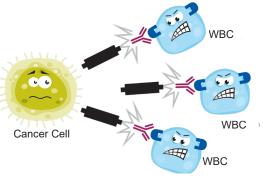
Image © Alberta Heatlh Services

What are checkpoint inhibitors?

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

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.



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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 Heatlh Services

The Basics of Your Treatment

What are the goals of treatment?

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 like 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.

Consenting to Treatment

Your Medical Oncologist (cancer doctor) may recommend checkpoint inhibitors and chemotherapy as part of your cancer treatment, but **you need to decide if you want** the treatment. To help make your decision, you need to know the:

- · Goals for treatment
- Risks and benefits to getting the treatment
- Other possible treatment options
- · Possible outcomes if you do not have treatment

Common Questions

How will I get my treatment?

- 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.
- 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.
- Pill form, either tablets or capsules or sometimes a liquid that you swallow by mouth. These are called oral medications.
- A needle the medication is injected into a muscle or just under the skin.



Terrie's Tip ~ cancer survivor:

"Feel secure and cared for in the treatment plan that has been created with you."



Download it from the App Store or Google Play.







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, they may also stop the treatment. We want you to feel safe.

Where will I go to get my 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. 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. Your treatment cycle starts

Break from treatment lets your body recover while the immune system continues its job

Netre Cicle

The treatment wakes up the immune system and attacks the cancer cells

Is the 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. 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.

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

Tell your healthcare team (doctor, nurse or pharmacist) about any other pills, injections, or medicines you take, including vitamins, or herbal remedies. Some systemic treatments do not mix well with other medicines 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)



Pregnancy

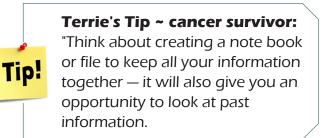
If you think you are pregnant, talk to your medical oncologist **before** you start your treatments. Treatment can affect an unborn baby.

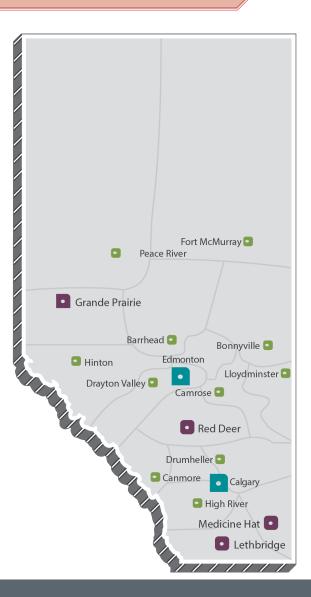
If there is a possibility that you or your partner could get pregnant, **you need to use some form of birth control** before and during treatments.

If you are planning to have children, make sure you ask your oncologist when it would be safe to try after treatment.

Care Closer to Home

There are 17 cancer centres in Alberta. Depending on where you live, you may be able to receive some or all treatment or support services closer to home. For example, some patients start their treatment in Calgary or Edmonton, and complete it at a cancer centre closer to home. Talk to your doctor or clinic nurse at your next visit to see if this is an option for you.





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

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
- $\hfill\square$ Government identification and your healthcare card
- $\hfill\square$ A book or electronic device (tablet/iPad) to help pass the time
- □ Questions you have written down to ask your healthcare team
- □ Bring all of your medications



• Wear comfortable clothes

 Don't schedule other activities or appointments for the first treatment day



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.



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.

After Your Appointment

- Follow any special directions your healthcare team gave you
- · Keep track of how you feel using your symptom tracker
- · 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.

- Keep your list up to date
- Share your list with your healthcare providers at your appointments

Your Systemic

Cancer Care

Treatment Appointment

- 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

Safety at Home



Most systemic treatments (**page 5**) are very strong medications, so there are some special things you or your caregiver need to do to keep you and the people (and pets) around you safe.

Why do I need to be careful at home?

Systemic treatments leave your body through fluids and wastes like urine, stool or vomit. When people or pets come in contact with affected waste or fluids, it can be harmful and they could also get side effects.

Generally, it can take up to 48 hours for systemic treatments to leave your body. It's important to **follow these safety precautions while you are taking your treatment and for 48 hours after you finish your treatment.** Some treatments stay in your system longer than 48 hours. Ask your health care provider if this applies to you.

Is it safe to have contact with others when I am taking these treatments?

Yes. Being with your loved ones is important. Eating together, enjoying favourite activities, hugging and kissing are all safe.

Is it safe to be sexually active?

Most often, yes. There may be some medication in vaginal fluid and semen up to 48 hours after treatment, so use a condom to keep you and your partner safe. If you need to do this longer than 48 hours, your nurse will tell you. You and your partner should also avoid getting pregnant during treatment.



Handling Body Fluids and Waste at Home

How do I handle my body fluids or wastes? Using the toilet:

- It is safe to use the same toilet (septic or city sewage) as other people
- Men should sit when using the toilet to avoid urine from splashing
- Flush the toilet 2 times (with the lid down) after you use it
- Wash any skin that touched urine or stool
- Wash your hands well with soap and water
- Use your own hand towel or paper towel if possible
- Clean any waste on the toilet with soap and water including the lid and handle

If you do not have control of your bladder or bowels:

- Use a plastic-backed pad, diaper or sheet that's disposable to absorb urine or stool
- Change the diaper or pad as soon as it gets soiled
- Wash any skin that comes in contact with the urine or stool with soap and water
- Wear disposable gloves when you handle the waste

If you have an ostomy:

- You or your caregiver should wear disposable gloves when you empty or change the bags
- Wash your hands with soap and water after you remove your gloves

If you vomit (throw up):

Try to vomit in the toilet if possible for easier clean up. Flush the toilet 2 times (with the lid down) after you use it.

If you use a bucket to vomit in:

- Wear gloves when you empty the bucket
- Wash the bucket with soap and water after each use
- Wash your hands with soap and water after you remove your gloves

What if my body wastes spill?

- Always wear disposable gloves
- Use paper towels, toilet paper or disposable absorbent pads to soak up as much of the spill as possible
- Wash the area well with soap and water 3 times.
- Put all of the materials in a bag and doublebag. Tie tightly.

What do I do with soiled laundry?

- · Wear disposable gloves when handling the soiled laundry
- · Wash them separately from other clothes and linens
- Wash through 2 complete washing machine cycles before you wear or use them again

What do I do with the garbage?

- Anything that may have come in contact with your body fluids must be handled with care. Wear gloves when you handle anything soiled.
- Put things you cannot flush down the toilet in a garbage bag, and tie it tightly.
- Put this bag in a second garbage bag. Remove and throw away your gloves into the second garbage bag also. Tie it tightly. Wash your hands well with soap and water.
- Once the garbage is double-bagged, you can throw it out with your regular garbage.
- · Keep garbage out of reach of children and pets.

If you use a bedpan, urinal or commode:

- Wear gloves when you empty it
- Wash it with soap and water after each use
- Wash your hands with soap and water after you remove your gloves



Disposable nitrile gloves offer the best protection when you're handling body fluids and waste. You can buy them at your local pharmacy.

Handling Cancer Medications at Home

You may need to take some of your treatment at home — this could be in the form of an injection, pills, or maybe liquids. Whatever the form, you need to make sure you know how to handle them safely, and what to do if some of it spills.

Oral systemic treatments (taken by mouth, pill form)

You may get systemic treatments that you'll need to take by mouth (oral). It's important that you and your caregiver handle these medications safely.

- Pour the oral medication into a medication cup or the lid of the pill bottle to pour into the patient's mouth. Wash the cup with soap and water
- If you do not have a medication cup, wear disposable gloves
- · Always wash your hands with soap and water after you are done



To stay safe:



- Do not chew, cut, crush or dissolve your medication unless you have spoken to the cancer centre pharmacist first.
- If the pills or capsules are damaged, do not breathe in the particles. If you accidentally get some in your eyes or nose, see **page 16** for what to do.



 If you like to use pill boxes to help you remember when to take your medications, you will need to use one just for your cancer medications. If you notice the pill box or pill vial has powder inside it from the cancer medications breaking, call your cancer centre pharmacist on how to handle it.



• Do not throw the medications into your garbage. If you have any extra oral medications, bring them back to your cancer centre pharmacy for proper disposal. Most local pharmacies are not able to dispose of cancer medications.

Injection systemic treatments

You may need to inject the treatments into a muscle or under the skin using a needle

- If you use a needle for your medications, you will get instructions from your nurse or pharmacist on how to safely handle the injection
- Wash your hands with soap and water after you're done
- Put all used cancer medication supplies such as syringes, tubes, cassettes, vials and bottles in a hard plastic container like a bleach or pop bottle and return them to your cancer centre

Can I travel with my chemotherapy medications?

Yes, you can travel with them, but check with your pharmacist or healthcare team for more information.

Sometimes you need to make special arrangements. For example, some medications need to be stored in the fridge.

When you travel, always seal the medications in a plastic bag.

If you are flying, keep your medications in:

- their original containers
- your carry-on luggage so you always have them with you

Handling Systemic Treatment Spills at Home



For more information: https://bit.ly/cleaningupspills

i

A spill is not just a liquid — it could be the powder from a tablet cut in half or a broken capsule.

	spill came in ntact with:	What you can do:
		 Wash your eyes under running water for at least 10 to 15 minutes.
C	My eyes	 Keep your eyes open when you do this.
		Get medical attention right away.
	My skin	 Wash the area with soap and running water for at least 10 to 15 minutes.
		 Tell your health care team as soon as possible.
		Wear disposable gloves
	My clothes or linens	 Wash your hands with soap and water after removing your gloves
		 Wash them separately from other clothes and linens
		 Wash through 2 complete washing machine cycles before you wear or use them again.
	A surface like the floor or table	Put on disposable gloves.
		 If it's a liquid, absorb the spill using a paper towel before wiping up.
		 Wash the area well with soap and water 3 times.
		 Put all of the materials in a bag and doublebag. Tie tightly.
	Paper materials (for example Kleenex, books, magazines)	 If you spill medicine on paper items you cannot clean, add them to the bag of garbage.

If you have a special pump for your treatment, use the spill kit the cancer centre gave you to clean up any spills from the pump.



Possible Side Effects

Are there side effects from the treatment?

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. Since you are on a combination of chemotherapy and checkpoint inhibitor, we need to look at the possible side effects of each treatment.

Checkpoint Inhibitors

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

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.

also attack some of the body's normal cells, which can cause side effects. These are called **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 on **page 19**. They can help you get the treatment you need, so do not try to manage these yourself.

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. Checkpoint inhibitors can affect these glands in the endocrine system, and cause 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.

Chemotherapy

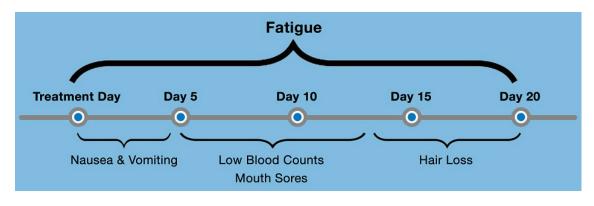
How does chemotherapy cause side effects?

Chemotherapy goes into the bloodstream, and travels around the body. While it works to attack the cancer cells, sometimes it affects the healthy cells too and this is what causes side effects.

When will the side effects happen?

Side effects can happen anytime during and after 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.

Here is a guideline showing when side effects can start:



If I have to go to the emergency room, what information is important?

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 what tests and treatment to start or when they should contact your medical oncologist to find out how to manage your side effects. These are special medications and medical oncologists are experts in knowing how to manage them. Remember to tell the triage nurse what type of treatment you are on and the name of the medication.



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

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.

This side effects section is split up into 2 categories:

- 1. Possible side effects of treatment (page 19)
- 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. (page 35)

2

Possible Side Effects of Treatment

Area affected:	What to watch for:			
Stomach and	Talk to your healthcare team if you have:		Go to the Emergency Room if you:	
intestines	I] Heartburn] Indigestion	☐ Have severe diarrhea (see page 20)	
	□ Burning feeling in □ your stomach] Nausea and vomiting	 Have vomited more than 10 times in 24 hours 	
	□ No bowel movements		\Box Cannot eat or drink	
	for 3 days		Have no bowel movements in 4 days	
Lungs	Talk to your healthcare team	if you have a:	Go to the Emergency Room if you have:	
	□ Cough with or without muc	ous	□ Difficulty breathing	
	□ Cough that is different than	n usual	☐ Chest pain	
	□ Cough with or without fever		☐ Shortness of breath	
Skin and nail changes	Talk to your healthcare tean □ Rash	n if you have:		
en angee				
			You know your body	
Muscles, joints	Talk to your healthcare team if you have:		best, and you can tel when you're feeling	
and nerves	\Box Aches and pains	well or unwell.		
	□ Severe muscle weakness/	fatigue	Tell your healthcare	
Liver	Side effects can happen to usually you will not notice healthcare team will use b make sure there is no chan liver function.	them. Your lood tests to	team right away if yo have any of these side effects so they can help you with them. You might nee medication to help	
	Talk to your healthcare tean	n if your:	treat them.	
	Eyes or skin turn yellow			
	□ Stools (poop) become ligh			
Mouth and	Talk to your healthcare team	if you have:	Go to the Emergency	
throat discomfort	Mouth sores are red or white hurt and either may or may n		Room if your: Mouth sores are preventing you from eating or drinking	

Area affected:	What to watch for:	
Low blood counts	Talk to your healthcare team if:	Go to the Emergency Room if you:
	You need to stay in a bed/chair for part to most of the day due to fatigue	□ Have a fever that is more than 38.3°C (100.9°F) at
	You have bruises on your body or small purple spots called petechiae (p-tea-key- our)	any time or 38.0°C–38.2°C for more than 1 hour
	eye) □ Your nose and gums bleed more easily	Cannot get out of bed or take care of yourself
	□ You have blood in your urine or stool	
Eyes	Talk to your healthcare team if you have:	Go to the Emergency Room if you have:
	□ Burning/pain	☐ Difficulty seeing out of the
	□ Blurred vision	sides of your eyes (loss of
	□ Irritated eyes	peripheral vision)
	Sensitivity to light	
Kidneys	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.	
Hormones	See page 28 for more information on hormones and the side effects	

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

Diarrhea

Diarrhea is an increase of 2 to 3 watery or loose stools (poop) 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

Fever

Some chemotherapies can put you at risk for developing an infection, and a fever may be the first or only sign of an infection. Infections can be life-threatening and need to be taken seriously.

What are the signs and symptoms?

A fever is a temperature of:

• 38.3°C (100.9°F) or higher at any time

OR

 38.0°C/100.4°F to 38.2 (100.8°F) for at least 1 hour

What can I do to monitor it?

You must have a **thermometer** at home when you are on systemic treatment. Use this to monitor your temperature as directed by your clinic nurse, or whenever you feel unwell.



If you have a fever, call your healthcare team right away, or go to your nearest emergency centre.

Remember to take your emergency letter with you to give to the healthcare team.



We recommend a **digital thermometer** because they give you an accurate temperature reading quickly.



Do not take any medications that help lower your temperature.

Some medications, such as acetaminophen or Aspirin[®] (A.S.A.), or ibuprofen can hide a fever. If you need to take a medication that contains this product, talk to your healthcare team first.

Here is a partial list of these medications:

Acetaminophen	Lowprin®	
Advil®	Methoxisal	
Alka-Seltzer® (plain and flavoured)	Midol®	
Anacin®	Oxycodan (Ratio brand)	
A.S.A.	Phenaphen	
Aspercreme®	Robaxisal®	
Aspirin®	Tecnal	
Bufferin®	Tylenol®	
Dodd's Extra Strength®	282 or 292 Tablets	
Ibuprofen		

There are many other things that may lower your temperature like cold and flu medications, and cough syrup.

This is not a complete list, so always check with your pharmacist to see if a medication you are buying contains A.S.A., acetaminophen or ibuprofen.

What can I do to help prevent infection?

Cleaning your hands removes or kills germs so you do not spread them to yourself or other people. This is the most important thing you, your family and friends can do to protect you from infection.

Clean your hands:

- after you cough, sneeze or blow your nose
- when you can see your hands are dirty or soiled
- after you use the bathroom

- · before you prepare or eat food, or feed someone
- after you have contact with blood or body fluids
- when you enter and leave a healthcare facility

You can use hand sanitizer or soap to clean your hands:



Hand sanitizer is best to use when:

- your hands don't look or feel dirty
- water and soap aren't available



- Soap and water is best to use:
- when your hands look or feel dirty
- before you eat or prepare food
- after you use the bathroom

Other things that will help prevent infection:

	Avoid sick people and crowds, influenza or other infections	J.	Ask your doctor if you should have seasonal or routine vaccines	
	Bathe or shower daily		Keep your lips moist	
	Keep your skin moist and healthy — use non-perfumed lotions		Wear sunscreen if outside — we recommend SPF 50 or higher	
	Use an extra soft toothbrush to brush your teeth and keep your mouth clean	· * •••	Do not empty the cat litter box — bacteria from the waste could increase risk of infection	
1	Clean your dentures with a toothbrush nightly	** •	Avoid being scratched by an animal	
	Wear gloves when gardening		Keep wounds/scratches clean and dressed	
	Practice good respiratory hygiene:			
	Cover your cough and sneezes with a tissue	Ψſ	Avoid eating meats or fish that are raw or not cooked properly	
	Sneeze or cough into your sleeve if you don't have a tissue		Wash all fruits and vegetables before you eat them	
	Clean your hands often			

The sanitizer should have 60% to 95% alcohol in it to work best. Treatment Day Day 1

Blood Counts

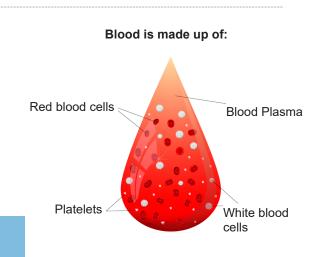
Low Blood Counts

Blood is made up different cells, but the most important are the white blood cells, platelets and red blood cells.

Chemotherapy can affect the blood cells, and can cause you to have low blood counts from days 7-14 after your treatment. Your blood count will start to slowly increase 2 weeks after your treatment.

Blood Counts After

Chemotherapy



If your blood counts become too low, you may need a blood transfusion. This may decrease the side effects you get with low blood counts. Platelets and red blood cells can be transfused but white blood cells cannot.

Remember low blood counts are:

Day 7

• temporary side effects from a drug or drugs you are getting to treat your cancer

Day 14

 most patients' blood counts will start to improve with time once the drug effects wear off around 14 days after you received it



You'll get a blood test 1 or 2 days before each treatment (or more often if needed) to check and see if your blood counts have increased enough to give you your next treatment.

Day 21

Counts

Blood

Platelets

Platelets help to clot blood or stop the bleeding when you cut yourself. If your platelet count is low:

- you may have bruises on your body or small purple spots called petechiae (p-tea-key-eye)
- your nose and gums may bleed more easily
- you may have blood in your urine or stool



If you notice any of these symptoms, let your healthcare team know right away.

White Blood Cells

White blood cells help your body fight off infection. There are many different types of white blood cells but the ones we watch closely are called neutrophils. They help fight infection in your body. If your neutrophils are low, you will not be able to fight infection as easily.

What are the signs and symptoms of a low neutrophil count?

A high temperature may be the first or only sign of a possible infection. Infections can be serious so make sure you monitor your temperature. See page 21 for more information on fever.

Signs of infection:

- · areas of redness or tenderness
- sore throat
- mouth sores

Red blood cells

- productive cough
- itching or burning in the genital area
- pain or burning when you pee
- the need to pee often

Red blood cells have a very important job to do in your body.

out, it gets rid of that waste.

They carry the oxygen around your

blood cells also carry carbon dioxide

to your lungs so when you breathe

body to keep it working. The red

If your red blood cell count is low, you may:

- feel more tired than usual (fatigue)
- become short of breath with minimal activity
- look pale
- feel cold
- feel dizzy
- become irritable

Here are a few tips you can do to manage these symptoms:

- Eat a healthy diet to help your body heal itself
- To get up from a lying flat position, sit up slowly and take a minute for your body to adjust, then stand up slowly. This may help with dizziness
- Take rest periods
- Do not try to do too much listen to what your body is telling you
- Try to build in regular walks as you are able. Adjust your walking pace and distance based on how you feel more brisk, further distances on days when you feel best, and slower, shorter walks when you have less energy

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Your neutrophil count should be at its lowest 7 to 14 days after treatment.

If your body's neutrophil count is too low, your treatment may be delayed so your body can heal first.



Tell your healthcare team right away or go to your nearest emergency centre if you have any of these signs or symptoms of fever or infection.



Tell your healthcare team if you have any of these symptoms.

Bleeding

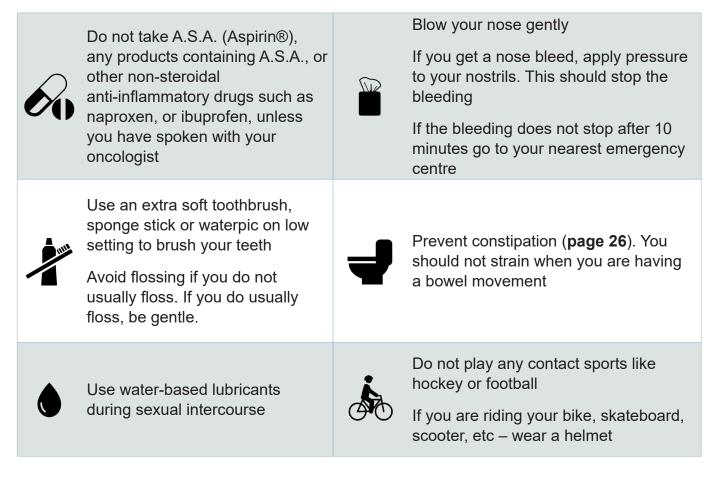
What are the signs and symptoms?

- · Cuts that will not stop bleeding
- A nose bleed that will not stop
- Blood in your vomit it can look like coffee grounds
- · Black or bloody bowel movements
- Red or pink in your urine
- Bleeding gums
- · Bruises but you're not sure what caused them
- Small purple or red spots under the skin.
- Dizziness, headaches, or changes in your vision
- Coughing up blood or blood in your saliva or phlegm

Why does it happen?

Some systemic treatment can cause a low platelet count and bleeding can happen when you have low platelets.

What can I do to help prevent or manage the bleeding?





If you have any of these symptoms, please call your health care team right away.

If your cancer centre is closed, go to your nearest emergency centre.

Constipation

Bowel movements are different for everyone. Some people have 1 or 2 movements daily, while others have them less often. It is important you know what is normal for you. Even if you are eating very little, you should still have small and regular bowel movements.

What is constipation?

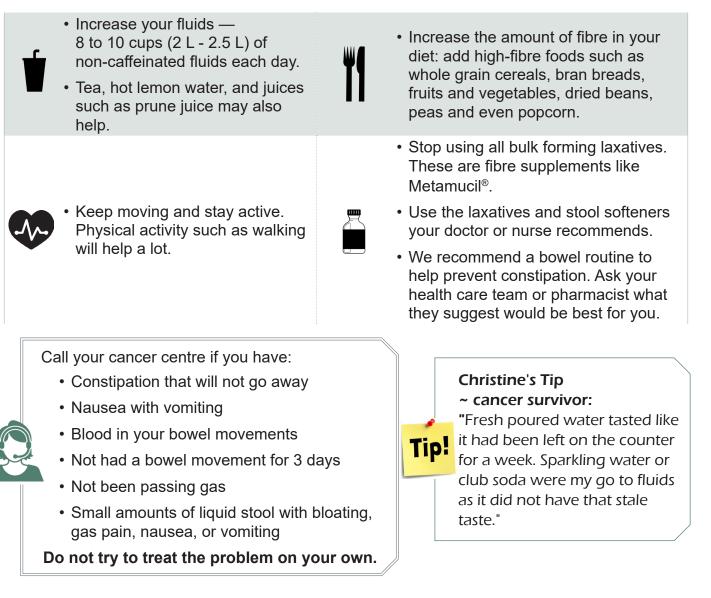
Constipation means either:

- having less bowel movements than you usually do
- or bowel movements that are difficult or painful because the stool is hard and dry

What causes constipation?

- · Taking certain pain medications
- · Taking other medications used with your cancer treatments
- Other factors like being inactive or dehydrated (not enough fluids)

What can I do to help prevent constipation?



Hair Loss

Not every cancer treatment causes hair loss. It depends on the amount or type of medication.

Why does it happen?

Some chemotherapy and targeted therapies can cause hair loss. In most cases hair loss is only temporary.

- You will probably begin to lose your hair between 14 and 21 days after the start of your treatment
- Some people notice an increase in sensitivity to their scalp before losing their hair
- If complete hair loss is expected, it usually takes
 3 7 days, but may take up to a few weeks
- It is possible you will lose hair from other places on your body such as eyebrows or pubic hair

What can I do to help manage my hair loss?

Before Treatment:

Be gentle with your hair:

- Do not colour, bleach or perm it.
- Try to limit your use of blow dryers, curling irons, or hot rollers.
- Limit your use of styling products, particularly those with alcohol or heavy perfumes.
- Avoid hair bonding or gluing.

During and After Treatment:

Be gentle with your remaining hair:

- Use a satin pillow case to decrease friction (rubbing).
- Use a soft brush or a wide tooth comb.
- Wash hair only when you need to.
- Use a gentle shampoo.

Tip!

Christine's Tip ~ cancer survivor:

"When my hair was falling out, it felt like it does when you hit your head getting into the car. Definitely get your hair shaved early. It was still tender but less so after the shave."

Questions to Ask Your Doctor or Nurse

- □ Are the drugs I am taking expected to cause hair loss?
- □ When will my hair begin to fall out?
- □ How much hair loss should I expect?
- □ Is there anyway of delaying hair loss?
- □ When can I expect my hair to grow back?

When the hair grows back, it can be a bit different. Most of the time these changes are just temporary, but it may become:

- finer or coarser in texture
- darker or lighter in colour
- curly or straight

Consider cutting your hair:

- · Short hair tends to look fuller
- It may make the transition to total hair loss a little easier



Consider shaving your head:

- This may give you a sense of control during this difficult time.
- It prevents losing your hair bit by bit.
- Your hair will grow back evenly and at the same length. This might allow you to go without a wig sooner.
- This will help decrease scalp tenderness some people have before hair loss.
- Remember to protect your scalp from sun and cold air.

Hypothalamus Pituitary gland

Thyroid and

parathyroid glands

Pancreas

Adrena

glands

Hair regrowth:

- Your hair may regrow between treatments and this is normal this hair is usually very fine and soft in texture.
- In most cases, hair loss is temporary. Your hair should start to grow back about 4 to 6 weeks after your treatments stop.
- Most people can expect about 1/4 inch of growth each month. Your hair may take up to 1 or 2 years to grow back completely.

Christine's Tip ~ cancer survivor:

"I had no idea how cold you can get when you don't have hair. Always have a soft hat for when you go to bed, even in summer!

I had drastic temperature changes so I would tuck it under my pillow if I got too hot. Trust me, later when I woke half asleep and freezing, it was no fun trying to find it. I knew where it was and it was easier to go back to sleep."

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.

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

These can include:

- Nausea and vomiting
- Fatigue or weakness (page 37)
- Headache new or will not go away
- Change in your appetite (page 35)
- · Cracked or dry skin/hair
- Change in your blood sugars

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

Ovary _____ (in female) 21) Testicle _____

(in male)

Endocrine

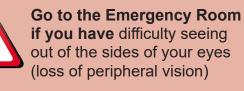
Pineal gland

system

Fever (page 21)Chills

Tip!

- Weight change (gain or loss)
- · Change in your mood or behaviour
- Trouble sleeping (page 41)
- Change in blood pressure



Hand and Foot Syndrome

This can happen with some cancer treatments. It involves the palms of the hands and the soles of the feet.

Why does it happen?

A lot of friction or pressure, like rubbing your hands or walking longer distances can sometimes cause the medication to come out of the small veins in your hands and feet.

What are the symptoms?

- It starts with dry, red skin on the hands or feet
- It may start to blister, especially on areas you use a lot
- It may happen on other parts of the body such as arms, arm pits, groin or backs of the knees

F;

What can I do to prevent or manage the symptoms?

🏏 Do:

- Wash your hands, bathe and shower with warm water
- Pat your skin dry after washing or bathing

Avoid:

- Hot water
- Putting hands and feet in water for a long time (washing dishes, long showers or baths)
- · Hot tubs and pools



Do:

- When you can, sit or lie on padded surfaces of chairs or mattresses, and elevate legs with cushions
- Place a pillow between your knees, or wear soft pajamas to prevent your legs from rubbing together while you sleep

Avoid:

• Tight dressings and adhesive tape if possible

Do:

Use an unscented lotion that's gentle on your hands and feet, especially in the creases of your skin. Examples of gentle creams: Bag Balm[®], Glaxal Base[®], Aveeno[®], Lubriderm[®], George's Cream[®], Lanolin creams

You may have numbress, tingling or pain

Peeling and splitting of the skin

Avoid:

• Rubbing too hard when you apply cream

Ć Do:

• Wear sunscreen SPF 50 or higher on exposed skin

Avoid:

Direct sunlight

え Do:

- Keep your hands and feet uncovered when you can
- Wear loose-fitting cotton socks or gloves at bedtime. This may help your body absorb the cream
- Wear loose-fitting clothes and comfortable, well-ventilated shoes with cushion soles

Avoid:

Tight-fitting clothing

Try to stay away from activities that cause pressure or rubbing to your hands and feet such as:

- washing roughly
- clapping
- jogging
- typing
- vigorous exercises
- gripping tools or appliances
- playing musical instruments

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Tell your healthcare team if you notice any redness or pain on the palms of your hands or soles of your feet. They can help you manage the symptoms.





Skin and Nail Changes

Skin and nail changes can happen anywhere on the body, and may cover small or large areas.

Your skin may:

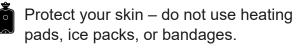
- Develop a rash
- Feel itchy, painful, or tight
- Develop blisters
- Peel or crack
- Develop patches that are red or discoloured
- Develop patches of purple spots
- Have patchy areas of hair loss
- Become more sensitive to sunlight

Changes to your nails may include:

- Redness, or sores around the edges of the nails
- Change in colour and texture
- Can become infected or lift away from the skin

How can I prevent or manage these symptoms?

- Use unscented creams and mild soaps that are gentle on your skin — ask your health care team or pharmacist what they recommend.
- Apply cream after you dry off from a shower, while your skin is still slightly damp, it will help to keep your skin moist and soft.
 - Avoid creams, soaps, and other hygiene products with alcohol or perfume. These can dry or irritate your skin.
- Keep your nails clean and cut short, but not too short.



Drink plenty of fluids to help keep your skin moist and healthy.



Pedicures and manicures are not a good idea during treatment — if you have too much skin removed or get a small cut, you could get an infection.



Remember to check around moist areas that are red — especially around the skin folds (under the breast, armpits, groin, behind the knees, elbows, around the bra line, and behind the ears)

Call your cancer centre if:

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

Go to the emergency room if you cannot speak to someone at your cancer centre.

- Take short showers or baths in lukewarm, not hot, water.
- Pat your skin dry rather than rubbing it dry.



If your lips are dry, apply lip balm (see page 40 for some suggestions).



Shave less often and use an electric razor or stop shaving if your skin is sore.



- Use sunscreen we recommend SPF 50 or higher when you go outside.
- Wear a hat with a wide brim.



Eat a healthy diet.



Wear gloves when you work in the garden.



Mouth Sores

Why does it happen?

Treatment can sometimes cause mouth sores, which can lead to an infection if your blood counts are low. You may have mouth or throat pain that starts about 5 to 7 days after your treatment.

What can I do to help manage my mouth sores?



Brush your teeth with an extra soft toothbrush after you eat

Do not use mouthwashes that contain alcohol - these can dry your mouth and irritate it



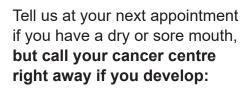
- Check your mouth in a mirror if you have pain or tenderness in your mouth
- If you have dentures or partials:
- Remove your dentures when you do your mouth care
- Brush and rinse your dentures after every meal



Floss your teeth gently and only if you already floss. Your healthcare team may ask you not to floss at all



- At bedtime, clean with a denture toothpaste and a denture brush before you soak them overnight
- Store your dentures in a denture cup with clean water
- If your mouth is sore, leave your dentures out or use them only when you eat



- Mouth sores (ulcers)
- Fever
- Difficulty swallowing
- White patches in your mouth
- Bleeding gums that do not stop after 2 minutes

Dental services are not insured in Alberta, but some people have dental coverage through their work or private insurance.



If you do not have dental coverage, you may qualify for funding based on your financial need. If you need coverage, Cancer Care Alberta Social Workers can help you and your family look at the financial supports available.



Before you start treatment, talk to your health care team about any dental work, including teeth cleaning you need. Your Tip! dentist and oncologist may need to work together to figure out when to do your dental care.

For a dry mouth or throat:

- sip water, juices, and other fluids throughout the day
- suck on sugar free candy or ice chips
- chew sugarless gum
- use a mouth moisturizing spray or gel, such as Biotene® oralbalance gel®, Biotene Moisturizing Mouth Spray[®], Mouth Kote[®], or Moi-Stir[®]. You can buy these at your pharmacy. Talk with your pharmacist if needed
- rinse your mouth often with homemade mouthwash (see the tip box below)

Homemade Mouthwash

Rinse your mouth with homemade mouthwash to help keep it clean and healthy. Rinse after you eat and as needed.



Tip: You can either use:

 1 tablespoon (tbsp) of baking soda mixed in 2 cups (16 ounces or 500 ml) of water. Store the mixture in the fridge and throw it out at the end of each day

Tip!

• Or you can use club soda



For dry lips:

- apply lip balm it will help keep your lips moist
- try not to lick your lips— it will dry them out more

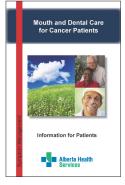
To prevent your lips from getting dry and cracked, use water-based or aloe-based lip care products like:

- Glaxal Base®
- Dermabase®
- Blistex®



Healthy eating for a dry or sore throat:

- Fruits that are soft, and have low acid such as all melons, canned fruits, or fruit nectars such as pear, peach or apricot
- Food that is moist, soft and easy to chew and swallow. Try adding extra gravies, sauces, butter and oil
- Foods that are high in protein and calories, such as yogurt, cottage cheese or cream soups
- Nutritional supplement drinks such as Boost Plus® or Ensure Plus®, or puddings
- You can also speak with a dietitian for helpful tips to keep up your nutrition



Get more information from the **Mouth and Dental Care for Cancer Patients** booklet available at your cancer centre.

Nausea and Vomiting

Not everyone will get nausea. Only some systemic treatments cause this and you will get medication to help prevent it. Fill your prescription at your local pharmacy before treatment starts.

How can I manage my nausea and vomiting?

- Eat a small, low-fat meal before your treatment avoid eating a heavy meal right before or after treatment.
 - Eat small meals 6-8 times a day rather than eating 3 meals a day.
 - Eat non-greasy, low fat foods that are not spicy or fried.
 - Eat cool foods without a strong smell such as: Jello[®], custards, dry cereals, crackers, toast, plain cookies, or smoothies.
 - Eat slowly and chew food well.
- Í
- Drink fluids before you eat.
- Drink 8-10 cups of fluid to keep hydrated (try diluted juices, popsicles[®], fruit drinks, weak tea and gingerale).



• Try not to lie down for at least 2 hours after you eat.



Anti-nausea medications help prevent nausea, so it's important to take them **before** your treatment as prescribed — **do not wait** to become nauseated before you take them.

Some anti-nausea medication can cause side effects such as:

- Drowsiness (so you may need to have someone drive you home from the hospital)
- Constipation (page 26)
- Muscle spasms
- Restlessness
- Tremors



If the nausea or vomiting lasts longer than 24 hours (even though you are taking your anti-nausea medications), or you have side effects from the anti-nausea drugs, call the contact number your health care team gave you.

Nerve Changes (Peripheral Neuropathy)

There are many nerves in your body that help control:

- How your body moves
- What your body senses hearing, tasting, touching, smelling, and seeing
- Your heart, bowels, lungs and other organs

Cancer treatments can affect these nerves, which may decrease your ability to feel sensations. These symptoms can be temporary or permanent.

What are the possible side effects?

Cancer treatments can affect the smaller nerves in your hands, feet, and other parts of your body.

The more common symptoms are:

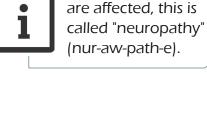
- Burning feeling or pain
- A feeling that your hands and feet are being squeezed
- Tingling in your fingers and toes
- Numbness or less sensation (feeling).
 For example, you may not feel cold or hot temperatures, have difficulty picking up coins, or be unable to do up buttons on your clothes

What can I do to manage these symptoms?

You and your health care team will decide how to manage these symptoms. You may get:

- · medications to help with the symptoms
- a referral to a physiotherapist or occupational therapist to help maintain your muscles, improve your movement, or balance if it's affected
- speech therapy if your speech is changed by the cancer or the treatment

There is nothing you can take to prevent the damage to the nerves. What you can do is keep a healthy lifestyle — eat healthy, exercise, and decrease how much alcohol you drink. If you are diabetic, keep your blood sugar levels in a normal range — diabetes can cause neuropathy too.



When your nerves



The nerves in your hands and feet are called "peripheral nerves" because they are the farthest from your spinal cord and brain.

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

What can I do to maintain or improve my appetite?

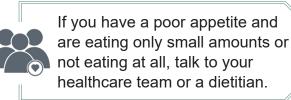
- Try new foods and drinks to find flavours that taste good to you.
- Make a list of foods you like. Eat them often, even if you eat the same foods over and over for awhile.
- Choose soft foods that need less chewing.
- Don't eat foods that taste bad to you.
- If your mouth is dry, try to increase the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



Blood Clots

Blood clot in the leg (deep vein thrombosis)

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 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



- 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



Blockage of a vessel in 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, please go to your nearest emergency room 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.

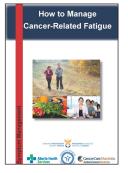
Fatigue may make you feel:

- 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

What can cause fatigue?



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



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

- weight loss
- stress
- cancer treatment
- cancer

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
- 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.

protein
changes in your daily schedule or interrupted sleep schedule

poor nutrition or getting enough calories and

- when time e routing
- 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.
 - 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



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 periods may stop
- early menopause

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 getting someone pregnant?

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?

Most often, yes. There may be some medication in vaginal fluid and semen up to 48 hours after treatment, so use a condom to keep you and your partner safe and prevent pregnancy. If you need to do this longer than 48 hours, your nurse will tell you. You and your partner should also avoid getting pregnant during treatment.





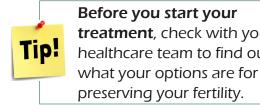
Before you start your

preserving your fertility.

treatment, check with your

healthcare team to find out

Speak to your healthcare team and they can refer you to psychosocial services.



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. Treating your pain will help you have a better quality of life.

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 them 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.

What causes cancer-related pain?

- cancer tumour or symptom
- cancer treatments
- · other symptoms like constipation or nausea
- · emotional, social and spiritual impact of cancer

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.
- Ī
- 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.



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.

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.

- stress or anxiety
- medical procedures and tests
- · other health factors
- medications

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 may include nausea and vomiting, drowsiness or constipation.

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

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 ٠ balancing a check book

What can I do to help with brain fog?



 Write things down in a journal Make lists Keep a calendar of when you have appointments and important events

· Drink enough fluids and eat a healthy diet

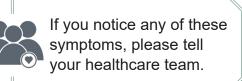


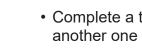
• Put things back in the same spot you always do, for example keep car keys in the same drawer

- Fatigue
- Depression
- Impaired sleep

Feeling:

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





Complete a task before you start



· Physical activity

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?

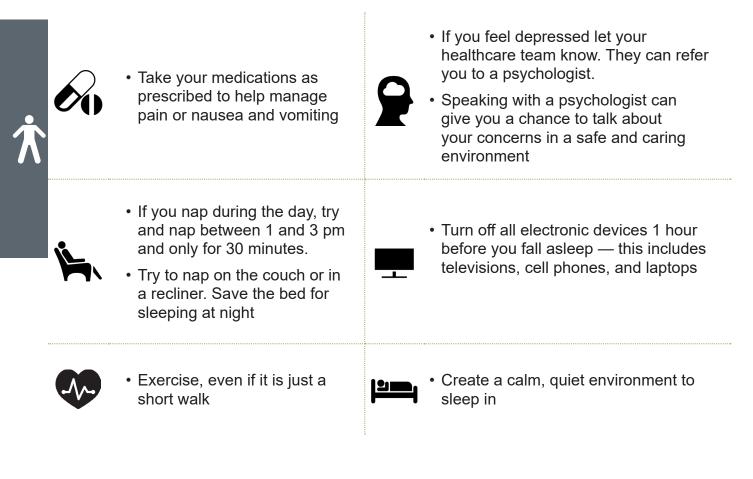
- Difficulty falling asleep
- Difficulty staying asleep
- Sleeping more than usual but not waking up feeling rested
- · Waking up earlier than you normally do

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 (page 39)
- Fatigue (page 37)
- Depression (page 43)
- Mood

What can I do to help improve my sleep pattern?



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.



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.

What are signs and symptoms of anxiety?

- Tense muscles
- 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

Feeling restless, worried, or not able to relax

- 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
- Waiting for test results
- Dealing with an anxiety disorder before you had cancer
- Medications, like steroids or some anti-nausea medications
- Fear of cancer coming back, suffering, or dying
- Having new symptoms that scare you

- Worrying about your family, especially if you have kids
- Feeling like you have no control over your life
- Worrying about money, your job and other practical things
- · Feeling badly from side effects like nausea and pain
- Depression





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.

look in the **Newly**

Diagnosed With

Cancer Book



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

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

- Support systems and how good they are
- History of mental health issues
 - 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
 - Feeling isolated

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

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:

Emotional and mental symptoms:
 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



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



What can I do to help my anxiety or depression?

Find support:

- Talk to someone you trust and who listens — friends, family or co-workers.
- **I** 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.
- Get a good sleep this can give you more energy and help you feel better emotionally.
 - Try writing in a journal or expressing your feelings through art.

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.

Some tips to help you live 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

Alcohol

Tip!

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

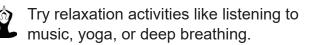
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Tips from the Canadian Cancer Society to help you reduce your alcohol intake:

- Choose the smallest serving size.
- Keep at least a few days each week alcohol free.
- Eat before and while you are drinking. Don't use alcohol to cope with stress.
- Plan ahead and set a limit on the amount you will drink.
- 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.
- Avoid salty snacks such as potato chips or nuts while drinking alcohol.
- Drink alcoholic beverages slowly and space out your drinks.

- 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.



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

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

> For more information about living well during treatment, visit:



cancercarealberta.ca



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

Higher energy foods without protein:



avocado, dried fruit, granola, cream and wheat germ



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.



protein powders and nutrition supplement drinks



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



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 can help:

- 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
- reduce how severe the side effects can be

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.

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. For more information and tips, visit Alberta Quits. www.albertaquits.ca



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

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

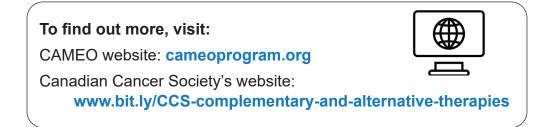
- vitamins
- massage
- hyperbaric oxygen treatment
- acupuncture

herbal remedies

• 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.



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 long-term form of support

What can palliative care do?

Palliative care can help patients and families live life to the fullest. Palliative care: Improves quality of life by • managing symptoms such as pain and nausea

 addressing anxiety, depression or spiritual concerns Helps with practical concerns by providing support with goals of care decision making and advance care planning

coordinating
 referrals

Supports people around the end of life by:

- explaining what to expect at end of life
- connecting to grief

support

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)

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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