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

Read about:
- what immunotherapy 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 health care team

You may be able to attend a class at your cancer centre before you start your treatment. This will help you prepare for common side effects, know who and when to call, and what to do in emergency situations.

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 health care team to review it with you.

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

For more information:
Other Alberta cancer care resources are available at your cancer centre or online — www.cancercontrolalberta.ca

Patient Guide (information and phone numbers for your cancer centre)
Sources of Help (supports and resources)

Find community support resources with Alberta 211

Terrie’s Tip — cancer survivor: “Information is power — the more you understand your situation, the better the partnership you create with your health care team.”

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

Disclaimer
Products listed in this booklet are just examples, for information only — AHS does not endorse specific products.
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**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."
Just Diagnosed
There are many different types of treatments used to treat cancer: surgery, radiation treatment, and systemic treatment. One type of systemic treatment is immunotherapy.

For a simple explanation of what the different types of treatment are, we'll use a garden analogy.

**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.

**Body with Cancer**
Cancer cells are like weeds in your garden. Sometimes the soil lets the weeds grow and spread.

**Immunotherapy**
Immunotherapies are like adding a fertilizer to the soil. It helps to restore the garden's health, which helps remove the weeds.
Radiation treatment is like increasing the power of the sun with a magnifying glass and aiming at the weeds to damage them to try to get rid of them or so they cannot grow or make new plants. Sometimes other healthy plants nearby might get damaged as well.
Immunotherapy is different than other cancer treatments — instead of attacking the cancer cells directly, it turns your immune system on 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, fungus, 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 immunotherapy targets is called a lymphocyte.

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.
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 does immunotherapy work?

The immunotherapy 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.
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. Immunotherapy is one type of systemic treatment.

What are the goals of immunotherapy?

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 health care 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.

Terrie’s Tip ~ cancer survivor: “Feel secure and cared for in the treatment plan that has been created with you.”
Consenting to treatment

Your Medical Oncologist may recommend immunotherapy as part of your cancer treatment, but you need to decide if you want to have immunotherapy. 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 immunotherapy
- Possible outcomes if you do not have treatment

How will I get my immunotherapy 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 immunotherapy 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 or 4 weeks. 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 immunotherapy 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 immunotherapy treatment?

Tell your health care team (doctor, nurse or pharmacist) about any other pills, injections, or medicines you take, including vitamins, or herbal remedies. Some immunotherapies 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 health care team if you have any changes to your medications. (See pgs 13-14)

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 immunotherapy affects an unborn baby.

Ask your oncologist when it would be safe to try to become pregnant after treatment.
In Treatment
Your Treatment Appointment

The Day Before Your Appointment

☐ Check your appointment slip to see if there are any special instructions and to check your appointment time

☐ 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 health care card

☐ A book or an electronic device (tablet/iPad) to help pass the time

☐ Questions you have written down to ask your health care 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 health care 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 health care 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 health care team can review your list to make sure this doesn't happen.

Let your health care 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 health care 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?

<table>
<thead>
<tr>
<th>Anything prescribed for you such as:</th>
<th>Anything you buy over the counter, such as:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Pills</td>
<td>• Pain killers</td>
</tr>
<tr>
<td>• Liquids</td>
<td>• Cold medications</td>
</tr>
<tr>
<td>• Patches</td>
<td>• Laxatives</td>
</tr>
<tr>
<td>• Inhalers</td>
<td>• Vitamins, minerals or supplements</td>
</tr>
<tr>
<td>• Eye/ear/nose drops</td>
<td>Others:</td>
</tr>
<tr>
<td>• Creams, lotions, and ointments</td>
<td>• Homeopathic, natural, or herbal remedies</td>
</tr>
<tr>
<td>• Samples of medication</td>
<td>• Any recreational drugs, such as alcohol or marijuana (cannabis)</td>
</tr>
</tbody>
</table>

Flu Shot (Influenza Immunization)

Talk to your oncologist first if you:

- have not yet started treatment
- are on treatment now
- finished immunotherapy 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 health care 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 health care team or a pharmacist.

Tell your health care 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](https://myhealth.alberta.ca/Alberta/Pages/know-your-medications.aspx)
Possible Side Effects
**Are there side effects from immunotherapy?**

There are possible side effects. Your health care 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 immunotherapy drugs may have different side effects.

**How does immunotherapy treatment cause side effects?**

When immunotherapy wakes 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 health care 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 health care 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 health care staff.*

This letter lets the health care staff know they should contact your medical oncologist to find out how to manage your side effects. Immunotherapies 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 immunotherapy.

**This side effects section is split up into 2 categories:**

1. Possible side effects from immunotherapy (pgs. 17-20)
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. (pgs. 18-29)
What side effects can I expect?
The types of side effects and how severe they are depend on which immunotherapy you receive. Your health care 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**

Talk to your health care team if you have any of these side effects. You may need medications to help with them, so do not try to manage these yourself.

<table>
<thead>
<tr>
<th>What to watch for:</th>
<th>Talk to your health care team if you have:</th>
<th>Go to the Emergency Room if you have:</th>
</tr>
</thead>
</table>
| **Stomach and Intestines** | □ Stomach pain  
□ Cramps  
□ Burning feeling in your stomach  
□ Heartburn  
□ Indigestion  
□ Nausea | □ Severe diarrhea (see pg 20) |
| **Lungs** | □ Cough with or without mucous  
□ Cough that is different than usual  
□ Cough with or without fever | □ Difficulty breathing  
□ Chest pain  
□ Shortness of breath |
| **Skin** | □ Rash  
□ Blisters | □ Hives  
□ Itchiness |
Possible Side Effects

### Possible Side Effects of Immunotherapy

#### Immune-Related Side Effects

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

#### Muscles, joints and nerves

<table>
<thead>
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<th>Side Effects</th>
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<tbody>
<tr>
<td></td>
<td>□ Aches and pains</td>
</tr>
<tr>
<td></td>
<td>□ Severe muscle weakness/fatigue</td>
</tr>
</tbody>
</table>

#### Liver

- Side effects can happen to the liver, but usually you will not notice them. Your health care team will use blood tests to make sure there is no change in your liver function.

#### Eyes

<table>
<thead>
<tr>
<th>Side Effects</th>
<th>Talk to your health care team if you have:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Burning/pain</td>
</tr>
<tr>
<td></td>
<td>□ Blurred vision</td>
</tr>
<tr>
<td></td>
<td>□ Irritated eyes</td>
</tr>
<tr>
<td></td>
<td>□ Sensitivity to light</td>
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</tbody>
</table>

#### Kidneys

- Side effects can happen to the kidneys, but usually you will not notice them. Your health care team will use blood tests to make sure there is no change in your kidney function.

#### Hormones

- See pg 19 for more information on hormones and the side effects

---

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

Tell your health care 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.

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

- Fever (pg 20)
- Chills
- Headache — new or will not go away
- Change in your appetite (pg 21)
- Cracked or dry skin/hair
- Change in your blood sugars
- Nausea and vomiting
- Fatigue or weakness (pg 23)
- Weight change (gain or loss)
- Change in your mood or behaviour
- Trouble sleeping (pg 29)
- Change in blood pressure

Go to the Emergency Room if you have:

- difficulty seeing out of the sides of your eyes (loss of peripheral vision)

Sometimes these side effects can be caused by other things, so talk to your health care team if you experience any.
Fever
Fever may be a normal response to treatment with immunotherapy.

When should I tell my doctor about fevers?

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

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

Call the contact number your health care team gave you

Diarrhea
Diarrhea is defined as an increase of 2 to 3 watery stools 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.

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

Go to the Emergency Room if:
- your diarrhea is severe — 5 or more times a day

My notes:
Possible 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 (pg 37).
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
- 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

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 centre right away.
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/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?

- 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 (pg 38) 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

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 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

**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?

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

Get more information from the **Fertility and You** booklet available at your cancer centre.
Possible Side Effects

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 health care 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 health care 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

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.
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 health care 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 health care 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
Possible Side Effects

### Problems with Memory

It is common for people with cancer to have problems remembering things, or take 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 health care team.

### What can I do to help with brain fog?

- Write things down in a journal
  - Complete a task before you start another one
- Make lists
- Keep a calendar of when you have appointments and important events
  - Get adequate sleep
- Drink enough fluids and eat a healthy diet (pg 36)
  - Physical Activity (pg 38)
- Put things back in the same spot you always do, for example keep car keys in a dish by the door
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 health care team may give you more information.

For more information, ask for these booklets at your cancer centre:

- “Sexual Health Information for Men with Cancer”
- “Sexual Health Information for Women with Cancer”
- “Low Sexual Desire: 10 tips for maintaining sexual activity”
Possible Side Effects

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 pgs 25-26)
• Fatigue (see pg 23)
• Depression (see pg 32)
• 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 health care 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 (pg 32)
• If you nap during the day, try and nap between 1 and 3 pm and only for 30 minutes.
• Turn off all electronic devices 1 hour before you fall asleep — this includes televisions, cell phones, and laptops
• Try to nap on the couch or in a recliner. Save the bed for sleeping at night
• Create a calm, quiet environment to sleep in
• Exercise, even if it is just a short walk (pg 38)
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.

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.

What are signs and symptoms of anxiety?
- Feeling restless, worried, or not able to relax
- Feeling moody or stressed
- Tense muscles
- Trouble sleeping

Some people have strong anxiety which can cause anxiety attacks. You may feel:
- Feelings of doom
- Shortness of breath
- 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.
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

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

If you feel depressed, let your health care 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.
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:

<table>
<thead>
<tr>
<th>Physical symptoms:</th>
<th>Emotional and mental symptoms:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Low energy</td>
<td>• Feeling hopeless or worthless</td>
</tr>
<tr>
<td>• Feeling sluggish or restless and agitated</td>
<td>• Not enjoying the things you used to enjoy</td>
</tr>
<tr>
<td>• Sleeping and eating more than before</td>
<td>• Feeling of guilt or regret</td>
</tr>
<tr>
<td></td>
<td>• Wanting to die</td>
</tr>
<tr>
<td></td>
<td>• Worsened anxiety</td>
</tr>
<tr>
<td></td>
<td>• Have trouble thinking or remembering things</td>
</tr>
</tbody>
</table>

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.
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:

- 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
- Improves quality of life by:
  - managing symptoms such as pain and nausea
  - addressing anxiety, depression or spiritual concerns

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 health care team
- Find out more about palliative care in Alberta or find programs and services in your community - [https://myhealth.alberta.ca/palliative-care](https://myhealth.alberta.ca/palliative-care) (ALBERTA)
- Check out [www.virtualhospice.ca](http://www.virtualhospice.ca) and [www.livingmyculture.ca](http://www.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: https://myhealth.alberta.ca/Alberta/cancer-systemic-treatment

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 health care 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.
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 from the 4 food groups:**
- vegetables and fruit
- grain products
- milk and alternatives
- meat and alternatives

**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 health care 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.
We know stopping or reducing the use of tobacco can be difficult and often takes several tries. By stopping or even reducing your tobacco use after a cancer diagnosis, you can improve your health and body’s response to treatment, whether it’s surgery, radiation or immunotherapy. Studies show many important benefits of quitting or reducing 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 tobacco cessation support or for more information:
Call the Cancer Wellness Clinic, a free tobacco cessation service available for cancer patients and their families across Alberta:
- Edmonton and Northern Alberta: 780-432-8236
- Calgary and Southern Alberta: 403-476-2988

Or visit [www.AlbertaQuits.ca](http://www.AlbertaQuits.ca) or call 1-866-710-QUIT(7848)
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 immunotherapy 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 health care team before you start a new exercise program.

Exercise is safe and good for you. If you have other health issues, check with your health care 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.
What is complementary and alternative medicine (CAM)?

Complementary and alternative medicine includes different healing approaches and therapies not considered to be standard medical treatments.

- **Standard medical treatments** are scientifically tested and researched and include treatments such as radiation, surgery, and systemic treatment (such as immunotherapy). 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.

- **Alternative medicine** is used instead of standard medicine.

It is your choice to use or not to use CAM. **Talk to your oncologist or family doctor if you are thinking about using CAM 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.

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**Does my health care team need to know if I am using CAM?**

**Yes.** Tell your doctor or nurse about anything you are taking or using. Some complementary medicine may make your treatment less effective. It's always best to talk to your health care team before you start any CAM.

CAM can include things like:

- pills
- vitamins
- massage
- hyperbaric oxygen treatment
- injections
- herbal remedies
- acupuncture

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**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.

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To find out more, visit:

- CAMEO website: [www.cameoprogram.org](http://www.cameoprogram.org)
© Alberta Health Services
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.

This book is meant to support the information your health care team gives you. It does not replace any information that your health care team gives you.

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