

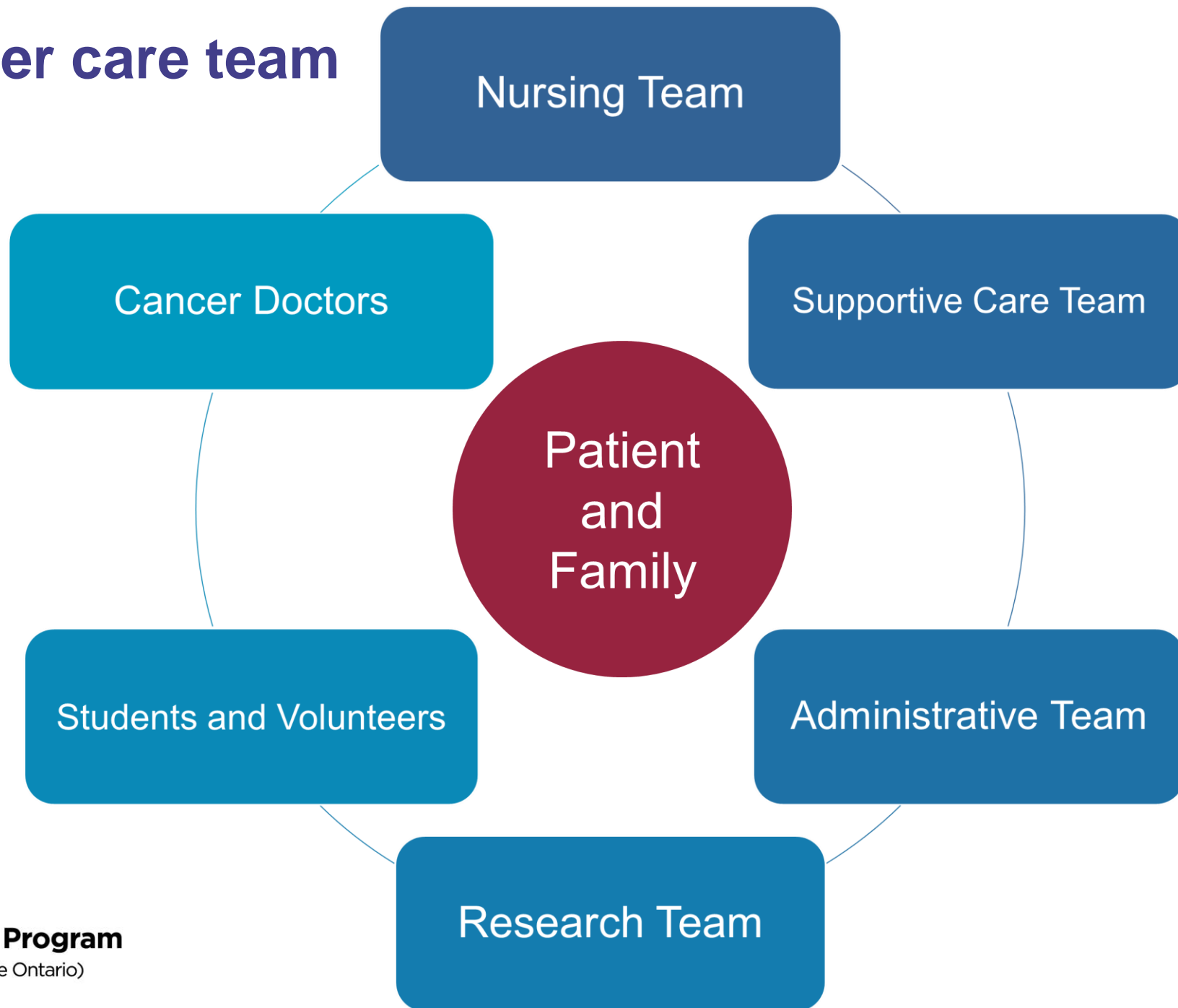
# Immune Checkpoint Inhibitor Class

For patients and families  
Last updated September 2023

# Class Overview

- Your Cancer Care team
- What are immune checkpoint inhibitor drugs
- Side effects and how to manage them
- Possible long term side effects
- What to expect during and after your immunotherapy treatment
- Resources available to you

# Your cancer care team



# Who to contact for help

## Cancer Centre hours:

**Monday to Friday 8:30 am to 4:00 pm**

- Call your Cancer Doctor's medical secretary.
- **1-800-567-5722** and enter the extension on your cancer doctor's business card.
- The medical secretary will communicate your concern to your nurse or doctor.

## After hours:

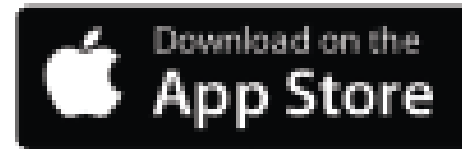
**Monday to Friday after 4 p.m. and 24 hours a day on weekends and holidays**

- Call **CAREchart@home**, after hours symptom management telephone service
- **1-877-681-3057**
- You will be connected to a specialized cancer care nurse who will help you.

**CAREchart  
@home**  
After Hours Symptom Management  
**1-877-681-3057**

**South East  
Regional Cancer Program**  
Ontario Health (Cancer Care Ontario)

**Kingston Health  
Sciences Centre**  
Centre des sciences de  
la santé de Kingston



## CAREchart@home app

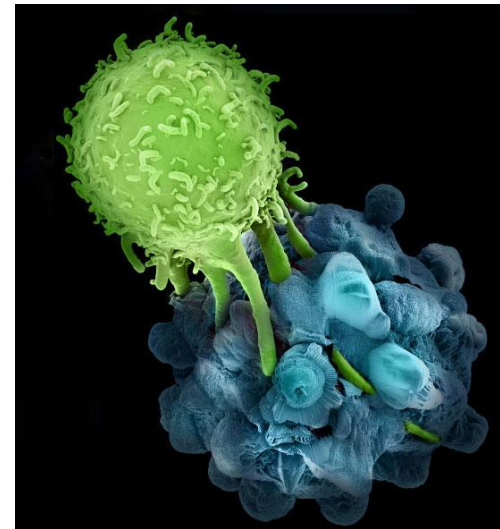
available to download from  
the App Store and Google Play

Features of the app:

- Pre-register and save time if you need to call
- Choose a telephone or video call with the oncology nurse

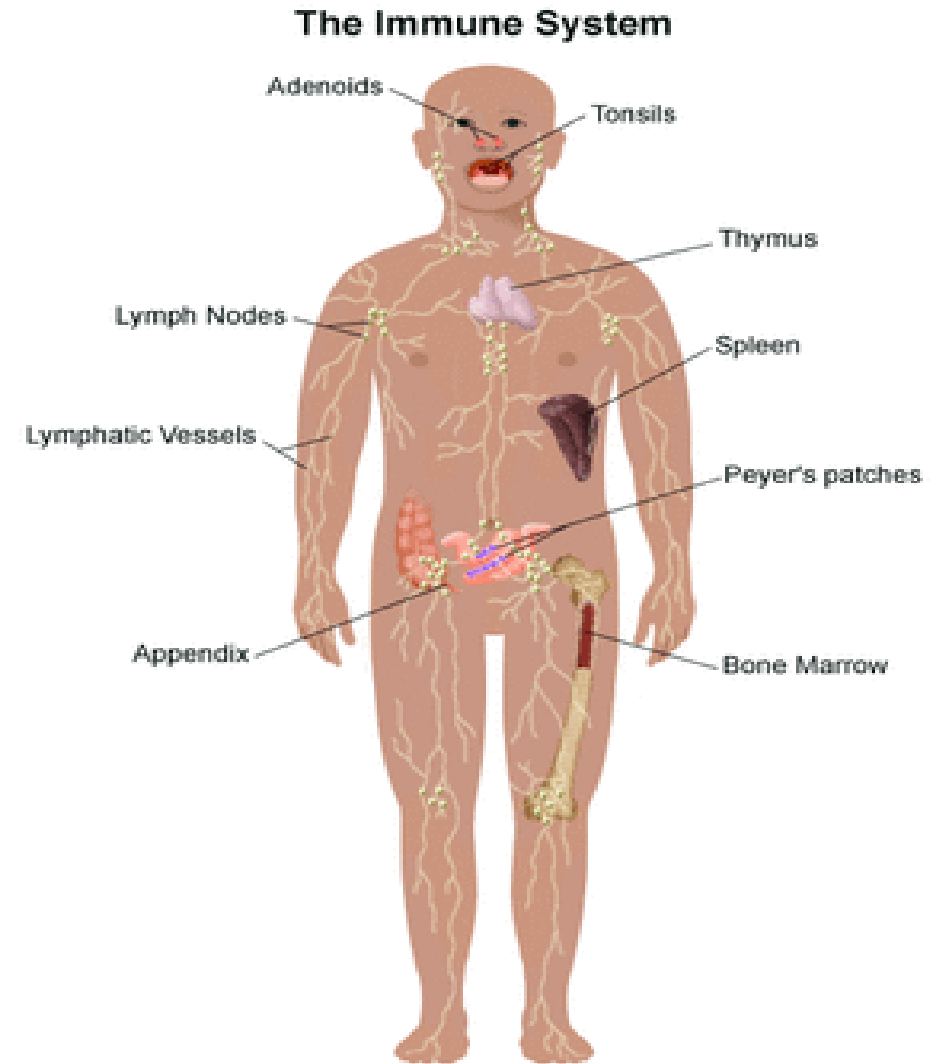
# What is Immunotherapy?

- A cancer drug treatment that uses your body's immune system to help fight cancer, just like it fights infections like the flu.
- Immunotherapy treatments help your body to know that the cancer is something it should try to get rid of.



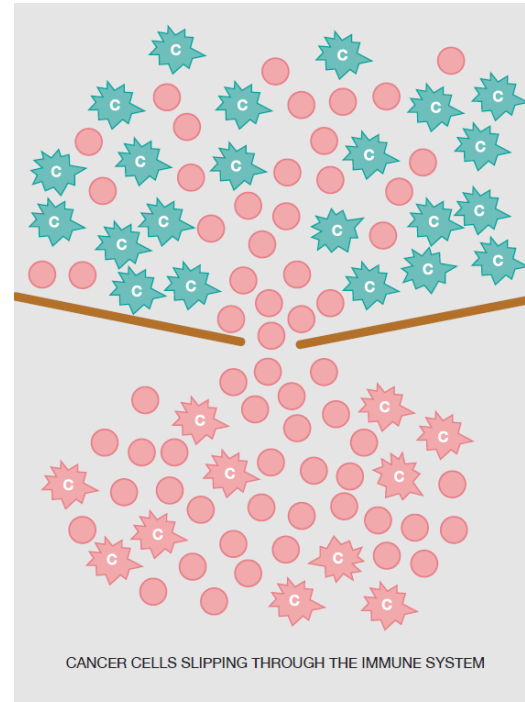
# The immune system

- A network of cells, tissues and organs that work together to find and destroy foreign invaders like bacteria and viruses or abnormal or unhealthy cells in your body.
- The most important job of the immune system is to know the difference between healthy and abnormal cells.



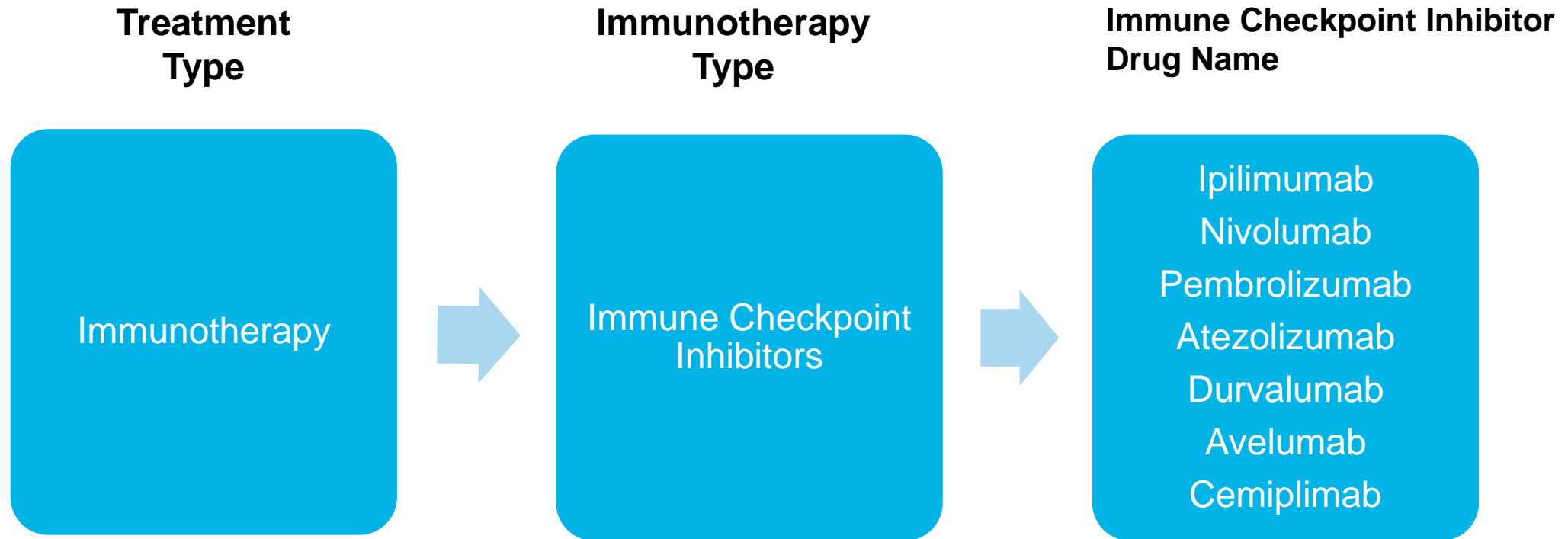
# The immune system and cancer

- The problem with cancer cells is that they come from our cells. This means that they can get past the immune system and continue to grow.
- However, the immune system has the potential to find cancer cells and respond.





# Immunotherapy Names



# Immune Checkpoint Inhibitor Wallet Card



**IMMUNE CHECKPOINT INHIBITOR Alert**

Immune Checkpoint Inhibitor drugs for cancer treatment are NOT chemotherapy. Side effects must be treated differently.

This card has information about your treatment and possible side effects. Side effects can be life-threatening.

**This may be a medical EMERGENCY.**

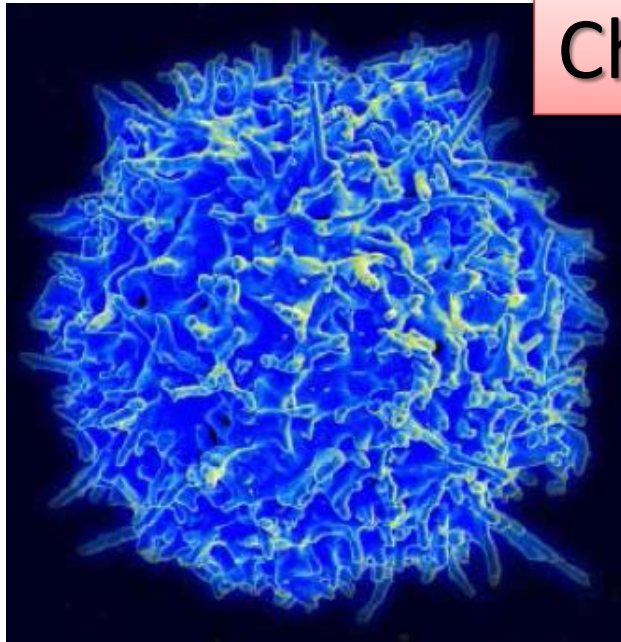
**South East Regional Cancer Program**  
Ontario Health (Cancer Care Ontario)

**Kingston Health Sciences Centre**  
Centre des sciences de la santé de Kingston

- Gives information about possible side effects and what to do if you have any of these side effects.
- Each time you go to the Emergency Department, show this card to the Emergency Department team as soon as possible.
- Keep this card with you at all times and for 6 months after your treatment has finished.

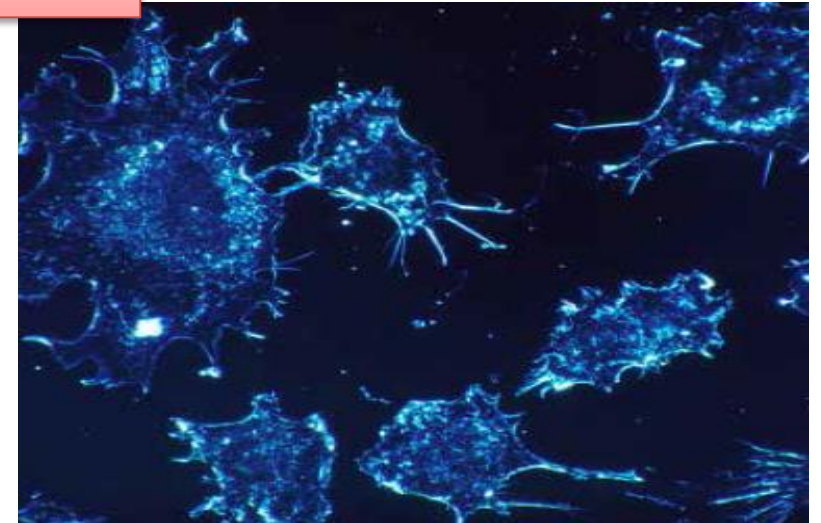
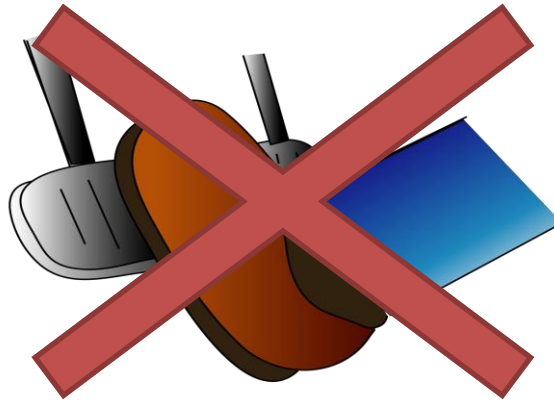
# Checkpoint inhibitors

- Takes the brakes off the immune system



Immune system "soldier"  
(T cell) trying to fight cancer  
cell

Checkpoint inhibitor given



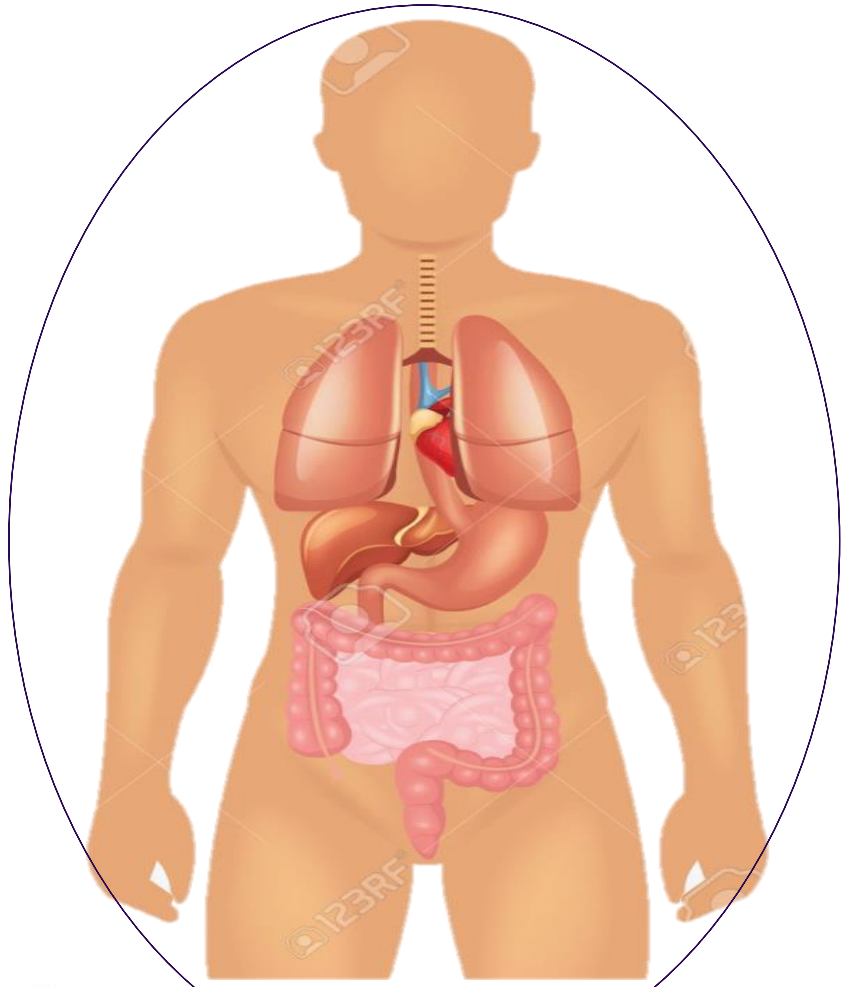
"invader" cancer cell

Cancer Centre of  
Southeastern Ontario

# Immune Checkpoint Inhibitor Videos

- **Immunotherapy and Side Effects** from Sunnybrook Hospital:  
English version <https://www.youtube.com/watch?v=CfKYcd8G0Cs>  
French version <https://www.youtube.com/watch?v=YtND4oNV3Gg>
- **What is Immunotherapy?** from William Osler Health System  
<https://www.youtube.com/watch?v=QZF33Mjl5W8>
- **Immunotherapy & Chemotherapy: What's the Difference?** from Cancer Research Institute  
[https://www.youtube.com/watch?time\\_continue=84&v=OhJyBWjcpvA&feature=emb\\_logo](https://www.youtube.com/watch?time_continue=84&v=OhJyBWjcpvA&feature=emb_logo)

# Side effects and how to manage them



Most common physical side effects include:

- Skin rash
- Diarrhea
- Liver changes
- Issues with the pituitary, thyroid, or adrenal glands
- Fatigue

# Important points about all side effects: the ABC's of immunotherapy

## A. Awareness

- Know what side effects to look out for (read your medication information sheets)

## B. Be alert: Close monitoring

- Pay careful attention and keep track of changes in symptoms
- Early awareness of side effects is very important

## C. Communication

- Report any changes to your cancer care team by phone
- **If you go to the Emergency Department → call your cancer care team**

# When to expect side effects

- Side effects can happen after one treatment or after many treatments.
- Some side effects can continue forever.

Your **awareness, close monitoring** and **good communication with the team** is essential!

- Some people can also have infusion reactions during the treatment.



# Taking Care of Your Emotional Health

You may be feeling some or all of these emotions:

Anger

Anxiety

Sadness

Fear or uncertainty

These emotions are normal and a natural response to stress.



## Tips on Managing

### Find Support:

Talk to someone you trust who is a good listener.

Let your cancer care team know how you are doing.

Social workers are available to see you and/or your family for support.

Get counselling to help you cope.

Focus on things that make you feel better.

Try relaxation activities.

Make lists of calming, enjoyable and useful activities.

### Take care of your body:

Eat well

Exercise

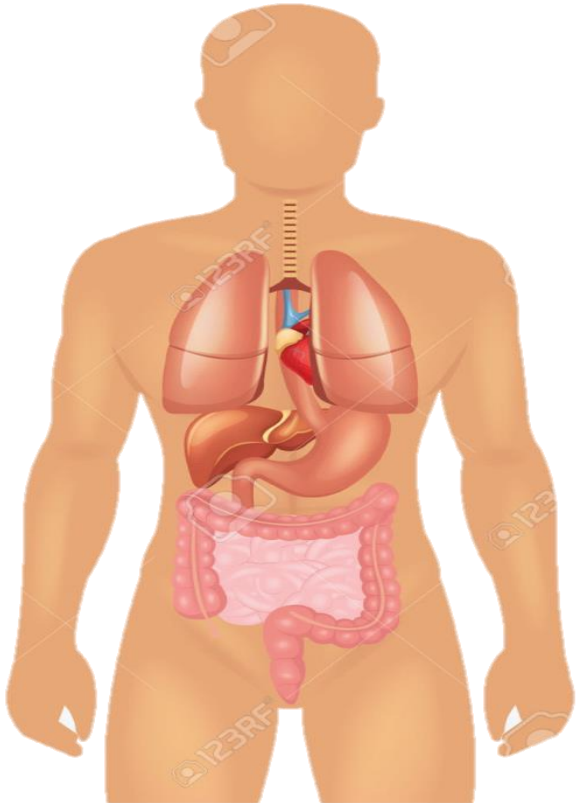
Improve your Sleep

Limit Alcohol



# Skin

## Rash or dry, itchy skin



- ✓ Contact cancer care team if you develop a new rash, no improvement of ongoing rash, or it becomes severe
- ✓ To prevent and treat dry skin:
  - ✓ Use skin moisturizer
  - ✓ Protect your skin from the sun and cold
  - ✓ Use sunscreen with UVA and UVB protection and a SPF of at least 30



# Skin

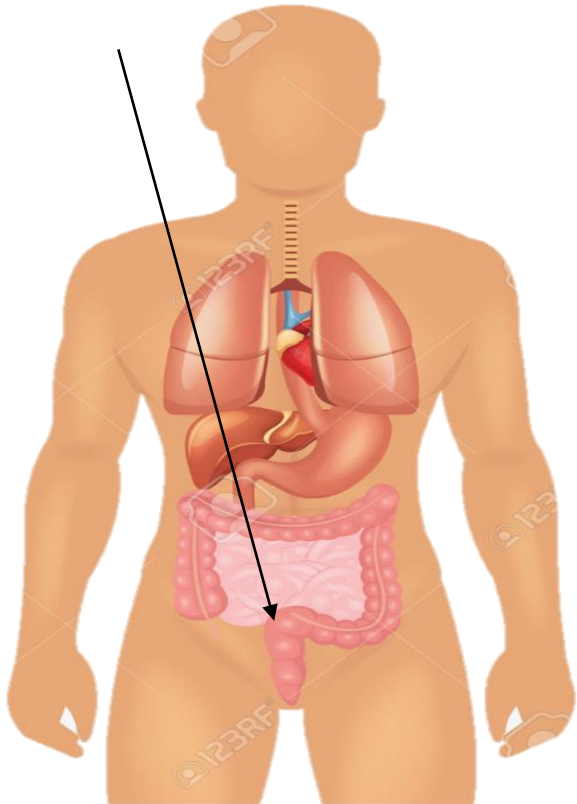
## Vitiligo

- ✓ More common in patients getting treatment for melanoma
- Can begin at any time, usually 6 months to 2 years after starting treatment
- **usually not reversible**
- Treatment: none
- Prevention: sunscreen



# Diarrhea and/or bowel changes

Loose, watery, or more frequent bowel movements (stool), or **any changes** in your bowel habits such as stomach pain or blood in your stool



- ✓ Do not take any anti-diarrhea medications or steroids until you have talked to your cancer care team
- ✓ **If you have 3 or more stools over your normal in 24 hours, call your cancer care team right away. Careful attention to early changes can prevent serious harm.**
- ✓ **Go to your closest Emergency Department and call your cancer care team if you have:**
  - ✓ **5 or more stools over your normal in 24 hours**
  - ✓ **Any blood in your stool**
  - ✓ **Diarrhea with fevers**

# Diarrhea



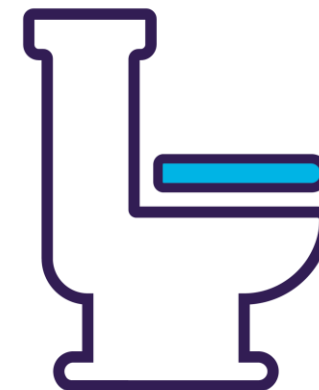
## Tips on Managing

- ✓ In addition to other measures you need to take on the previous slide, if you develop diarrhea try the following self-management strategies:
  - ✓ Drink at least 6 to 8 cups of liquids each day
  - ✓ Eat many small meals and snacks instead of 2 to 3 large meals
  - ✓ Avoid probiotics

✓ Use tips from the **diarrhea** patient guide

# Constipation

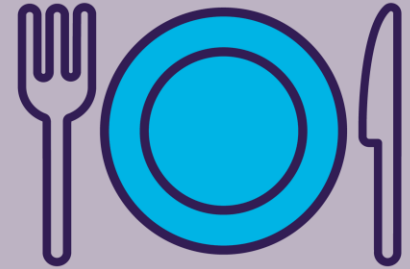
Common, but not an immune related side effect.  
Can be caused by other medications for pain or nausea.



## Tips on Managing

- ✓ Important to prevent
- ✓ Stay active
- ✓ Ask your doctor about laxatives
- ✓ **Drink lots of fluids**
- ✓ Eat more fiber foods (whole grain bread, fruit and vegetables)
- ✓ If you have not had a bowel movement for 3 or more days, call your doctor

# Nutrition



**Nutrition is an important part of your cancer treatment.**

**Eating well can help you to:**

- ❖ Maintain your body weight
- ❖ Improve your energy and strength,
- ❖ Lower the risk of infection
- ❖ Help your body with healing and recovery from cancer treatments.

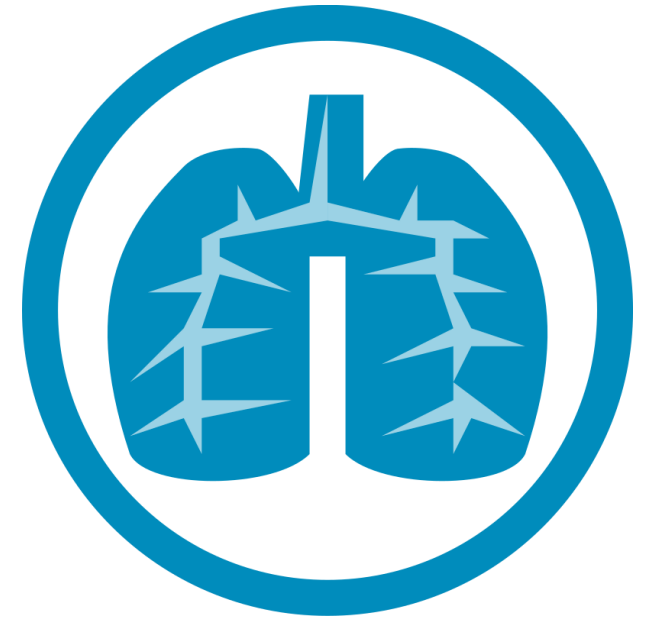
**Registered Dietitians are available to help you manage symptoms or side effects of treatment:**

- unintentional weight loss,
- loss of appetite
- trouble swallowing
- taste changes,
- sore or dry mouth,
- nausea, vomiting, diarrhea or constipation

# Breathing Problems

Changes in your breathing are uncommon but can be serious.

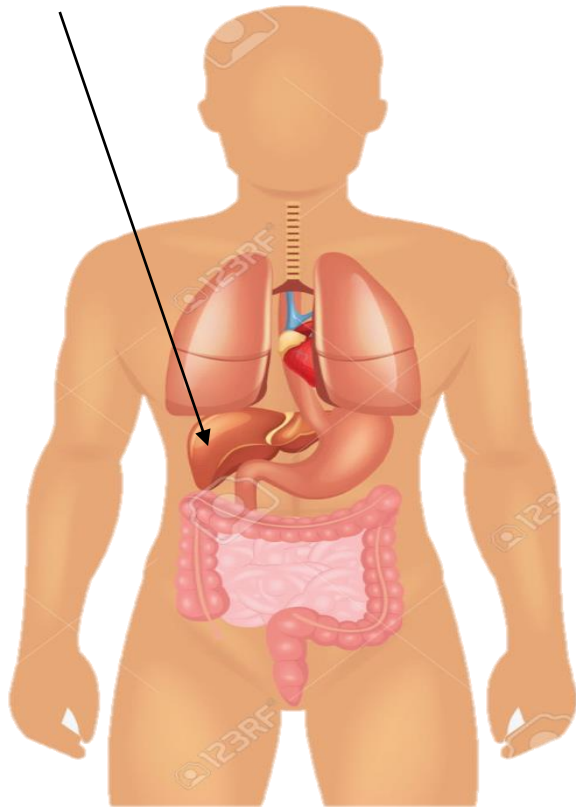
Call your cancer care team right away or go to your nearest Emergency Department if you have **trouble breathing, wheezing, coughing or chest pain.**





# Liver changes

Inflammation of the liver

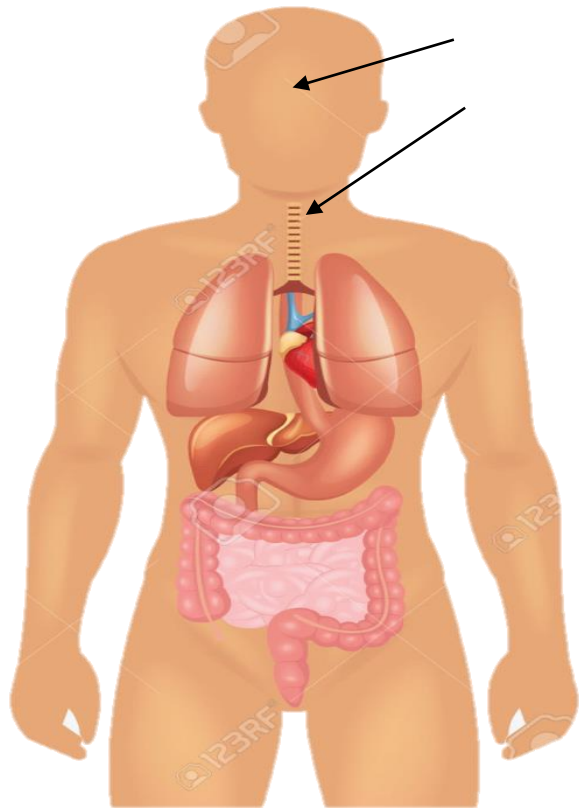


- ✓ Your team will monitor your liver regularly with a blood test.
- ✓ Tell your team if you notice yellowish skin or eyes, unusually dark urine or pain in your right side of your belly.



# Issues with the pituitary, thyroid, pancreas or adrenal glands (endocrine system)

Nausea, headache, fatigue, or vision changes

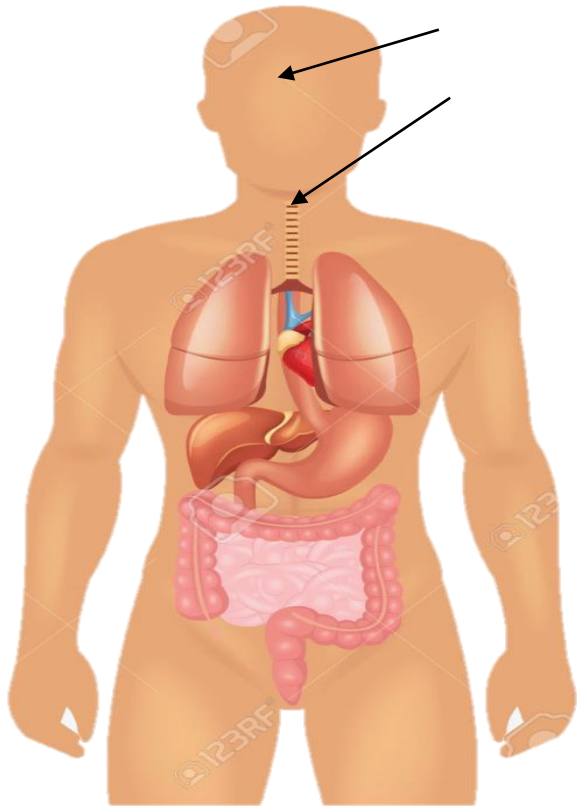


- ✓ Your team will monitor for changes regularly with a blood test.
- ✓ Tell your team if you notice any of the symptoms noted above.

Some patients may experience hyperglycemia (high levels of sugar in the blood).

Symptoms include: frequent urination, increased thirst and above symptoms.

# Issues with the pituitary, thyroid, pancreas or adrenal glands (endocrine system)



- ✓ Changes related to the endocrine system from immunotherapy are usually **permanent**
- ✓ This means if you develop one of these side effects, you may need life-long medications

# Eye Changes

Inflammation of the eye



- ✓ While on immunotherapy, you may have regular check ups with the eye doctors
- ✓ Tell your team if you develop new blurry vision or dry/gritty eyes

# Teeth Changes



- ✓ While on immunotherapy, you may develop a dry mouth
- ✓ This can result in cavities and dental complications
- ✓ Use a fluoride toothpaste and toothbrush with soft bristles
- ✓ See your dentist with any dental concerns

# Fatigue

Feeling tired or a lack of energy that does not go away with sleep or rest. Common but usually mild.



## Tips on Managing

- ❖ **Pace yourself, do not rush. Put off less important activities.**
- ❖ **Listen to your body. Rest when you need to.**
- ❖ **Use tips from “How to manage your Fatigue” patient guide**

[cancercareontario.ca/en/symptom-management](https://cancercareontario.ca/en/symptom-management)

### **Take care of your body:**

- ✓ Eat well and stay hydrated
- ✓ Exercise. Be active. Aim for 30 minutes of moderate exercise on most days. Start slowly and go at your own pace.
- ✓ Improve your sleep.

# What happens if I develop a fever?

A fever is a temperature of 38.3° C (100.9° F) once or 38.0° C (100.4° F) for over an hour

- ✓ If you develop a fever, contact your cancer care team
- ✓ If you develop a fever and also feel unwell or have other symptoms (including cough, diarrhea, rash or abdominal pain), go to the nearest Emergency Department **in addition** to calling your cancer care team

- You do not need to check your temperature on a daily basis when you are only on immunotherapy

# Important points about all side effects

- Treatment may be supportive (to help manage symptoms) or may require steroid treatment (pills or IV medications)
- You may need to be admitted to hospital or see a specialist to manage the side effect
- Some (more severe) may need a delay or stop in your treatment
- Some may result in permanent complications or require life-long medications



# Sexual Changes



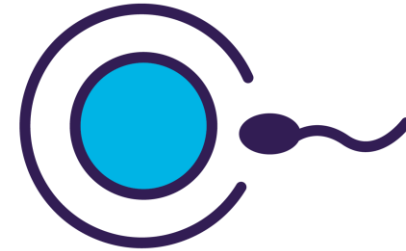
- Physical and emotional changes during treatment can cause sexual side effects
- Common side effects: loss of desire, painful intercourse, changes in orgasm or erection

## Tips on Managing

- ✓ Talk with a nurse, doctor or social worker
- ✓ Be open and honest with your spouse or partner. Talk about your feelings and concerns
- ✓ **If you or your partner are able to become pregnant, you must use birth control**
- ✓ Ask for a referral to the Cancer Centre Sexual Health Clinic



# Fertility Changes



- Immunotherapy can cause fertility changes in both men and women.

**If you plan to have children in the future or think you might want to, talk to your cancer care team before starting treatment.**

# Vaccinations



- Talk to your health care team if you are thinking about getting any vaccines for health or travel
- You should NOT have any live vaccines while on immunotherapy
  - Live vaccines include measles, mumps rubella, chicken pox, shingles, yellow fever, rabies, BCG (for tuberculosis), and typhoid. Nasal spray flu vaccines (ie. Flu-Mist) are also not allowed
- COVID 19 vaccines are safe for use during immunotherapy

# Safe handling of your bodily fluids

- There are no precautions for safe handling of your bodily fluids while you are on immune checkpoint inhibitors
  - i.e. you do not need to worry about protecting others from your bodily fluids while on immunotherapy
- If you are treated with both immune checkpoint inhibitors and chemotherapy, follow the safe handling precautions for chemotherapy



# **What to expect during your immune checkpoint inhibitor treatments**

# Cancer Centre Appointments

You will have two kinds of appointments related to your chemotherapy:



# Treatment Schedule

- Immunotherapy is usually given in cycles.
- Each cycle includes a clinic visit, a treatment visit and time off between treatments.



Clinic Visit



Treatment Visit



Time off

# Clinic Visit

## During this visit you will usually:

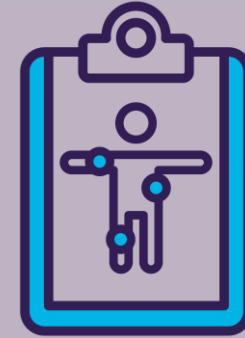
- ✓ Arrive 45 minutes before your appointment time for blood work.
- ✓ Get blood work done
- ✓ Fill out the “Your Symptoms Matter” questionnaire
- ✓ Be assessed by your Nurse and Doctor

## At this visit you should:

- ✓ Tell your team about how you have been doing and explain any side effects that you may be experiencing
- ✓ Ask your questions or discuss your concerns
- ✓ Bring a notebook to write down important information



# Your Symptoms Matter



- We ask you to fill out a symptom assessment self-questionnaire at every clinic visit.
- Your Symptoms Matter asks you to rate common symptoms on a scale of 0 to 10.
- **Your symptom scores help us to understand how you are feeling.**



Symptom Management Desk located on Burr 1

Scan this QR code to fill out the Your Symptoms Matter questionnaire on your device





# Treatment Visits

**Step 1: Register and get hospital ID bracelet**

**Step 2: Wait in treatment area waiting room**

**What will happen while treatment is given?**

- Sit in a recliner chair
- Nurse will start your IV (if required)
- Pre-medications may be given
- Immunotherapy treatment will start
  - Most patients do not feel pain or anything unusual. If you do, tell your nurse right away
- IV will be disconnected
- You may be given a prescription for medications to help with side effects



Cancer Centre of  
Southeastern Ontario

# Preparing for Treatment

- The registration clerk will phone you three days before your appointment date with your treatment time. You can ask the clerk how long you should plan to be here.
- Have someone available to drive you home after your treatment.
- Eat a light meal prior to your treatment (breakfast or lunch).
- You will see a Cancer Center pharmacist on your first treatment day.

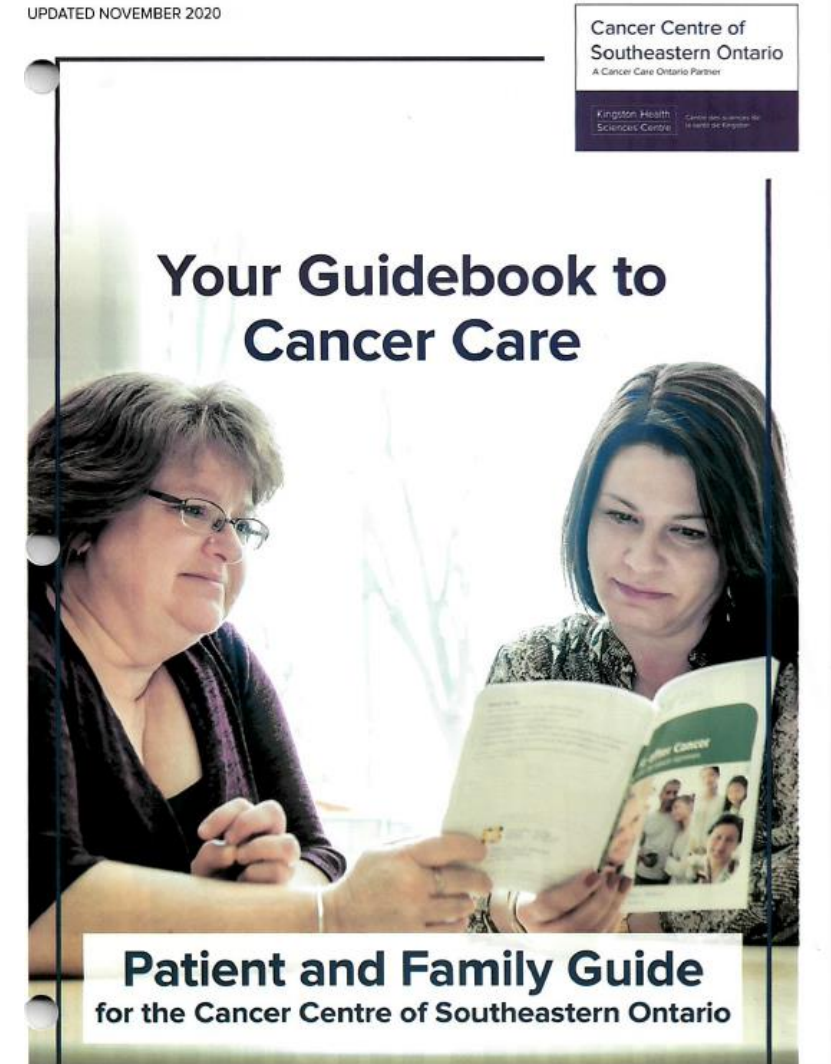
# What to Bring to Treatment Visits

- ✓ Your health card
- ✓ Private insurance information
- ✓ Wear a shirt with sleeves that can be rolled up
- ✓ Money to pay for possible prescriptions and parking
- ✓ Snacks or food
- ✓ Books, tablet, or laptop
- ✓ CAREchart@home wallet card
- ✓ List of your current medications
- ✓ Medications you take during the day
- ✓ A notebook to write down any important information

# Paying for Drugs

Your treatment plan may include drugs that are not paid by OHIP.

- ✓ Know what kind of drug coverage you have before you start treatment
- ✓ Refer to your **guidebook** to find out what you need to know before you start treatment
- ✓ Our **drug access coordinator** or **social workers** can answer your questions (contact information in the guidebook)





# Treatment Closer to Home

It may be possible to get your immunotherapy and other supportive treatments in:

- ✓ Napanee
- ✓ Brockville
- ✓ Perth

Ask your nurse or  
doctor for more  
information

# Things to know AFTER Immunotherapy

- Once you have finished your immunotherapy treatment, there is a small chance that you have some permanent complications that need life-long management
- There is also a small chance that some side effects can start after you have finished your immunotherapy (usually within 6-12 months of finishing your treatment)
- You may need to see a specialist for management of long-term side effects outside of your cancer team (family doctors, endocrinologists)
- If you have been discharged by your cancer team and develop a new medical problem, talk to your family doctor about whether it could be related to your immunotherapy

# Cancer Clinical Research

The standard cancer treatments used today were made and tested in clinical research studies years ago.

- If you are interested in learning more about research at the Cancer Centre talk to a member of your cancer care team or email  
CC-ClinicalTrials@kingstonhsc.ca
- Learn how clinical trials shape future patient care: <http://itstartswithme.ca/>
- Learn about the Canadian Cancer Clinical Trials Network: <http://3ctn.ca/>



# Services and Resources



- Canadian Cancer Society [www.cancer.ca](http://www.cancer.ca)
- Wellspring [www.wellspring.ca](http://www.wellspring.ca)
- Gilda's Club [www.gildasclubtoronto.org](http://www.gildasclubtoronto.org)
- Young Adult Cancer Canada [www.youngadultcancer.ca](http://www.youngadultcancer.ca)
- Community support groups and organizations



# Questions?

[www.kingstonhsc.ca/cancer-care](http://www.kingstonhsc.ca/cancer-care)

