

# Immunotherapy for Cancer Treatment: Immune-Checkpoint Inhibitors (ICI)

## Information for people with cancer and their families

Read this pamphlet to learn about:

- What immunotherapy is
- How ICI works
- What the side effects of ICI treatment are
- What to expect during ICI treatment
- What to expect after you finish ICI treatment



## What is immunotherapy?

Cancer immunotherapy is a type of cancer treatment that uses the body's immune system to prevent, control and kill cancer. Cancer immunotherapy is also called biological therapy.

There are different types of immunotherapy to treat different cancers. Your oncologist (cancer doctor) will choose the right immunotherapy medicine to treat your cancer.

Here is a list of the main types of immunotherapy used at Princess Margaret:

- Monoclonal Antibodies (MABs)
- Immune-checkpoint inhibitors (ICIs)
- Cancer vaccines
- Cytokines
- Immune cell therapy (such as, CAR-T, BiTE)

This booklet mainly focuses on Immune-checkpoint inhibitor (ICI) drugs. We will call them **checkpoint inhibitors** throughout this handout.

## How does immunotherapy work?

To understand how ICI work, it helps to understand how the immune system works.

The immune system is your body's normal defense system. The immune system is made up of cells (such as white cells called T-cell and B-cell lymphocytes), tissues and organs that protect you from harmful germs and diseases.

The immune system helps to:

- fight infections
- remove any abnormal, unhealthy or dying cells like cancer cells
- protect healthy cells from damage

Cancer cells can hide from the immune system by making themselves look like normal cells. By hiding from the immune system, cancer cells can continue to grow and spread. Both cancer and cancer treatment (such as chemotherapy), can weaken your immune system.

## **How can immunotherapy medicine help?**

Immunotherapy medicine works to:

- boost your immune system to make it stronger
- make the immune system better at finding and killing cancer cells
- bring cancer medicines, such as chemotherapy or radiation, straight to cancer cells

## **How do I know if the immunotherapy medicine is working?**

Immunotherapy is considered effective when your tumour shrinks in size or stops growing. Your doctor will order blood tests or scans of the tumour to check how your tumour is responding to the treatment.

## **What can I expect in my daily life during treatment?**

During immunotherapy treatment, you should be able to keep your normal routine. You can continue to do light exercise, eat the food you normally eat, drive a car, take care of others and work. Listen to your body and set your own limits as you go through treatment.

If your side effects are severe, you may need to limit or change your normal routine. Talk to your health care team if you need help on how to make changes.

## Can I get vaccinated during or after immunotherapy?

Yes, you can get vaccinated during or after your immunotherapy. Check with your oncologist when would be the best time to get your flu or COVID-19 vaccine.

## Is immunotherapy the same as chemotherapy?

Immunotherapy is not the same as chemotherapy. The table below shows how chemotherapy and immunotherapy differ.

	<b>Chemotherapy</b>	<b>Immunotherapy</b>
<b>How does it work?</b>	Chemotherapy attacks and kills cancer cells directly.	Immunotherapy boosts and supports the immune system to fight the cancer cells.
<b>How fast will the tumour respond to my treatment?</b>	The tumour may start to shrink soon after treatment.	It usually takes a while for the tumour to shrink. Sometimes the tumour may grow before it starts to get smaller. This does not mean that your treatment is not working.
<b>How long does the treatment effect last?</b>	Chemotherapy works as long as the medicine is in your system.	The effects of some immunotherapy on your immune system can last long after your treatment ends.

	<b>Chemotherapy</b>	<b>Immunotherapy</b>
<b>What causes side effects?</b>	<p>Chemotherapy attacks rapidly dividing cells, like hair, mucous membranes, stomach lining and intestines.</p> <p>Damage to these cells can cause side effects such as hair loss, mouth sores, heartburn, and diarrhea.</p> <p>Side effects usually happen during treatment and go away soon after treatment is done.</p>	<p>Immunotherapy can trigger an overactive immune system. An overactive immune system causes the immune system to attack normal cells as well as cancer cells.</p> <p>Damage to the normal cells causes side effects. Side effects can happen anytime during treatment. Some immunotherapy drugs can have side effects that last long after the treatment ends.</p> <p>See “What side effects should I watch for?” on page 9 to learn more about the different side effects.</p>

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## **How does ICI work?**

Cells in our immune system called T cells produce proteins called checkpoints. Checkpoint proteins control how your immune system responds to cancer cells.

Different checkpoint proteins work in the body in different ways.

- Some checkpoint proteins turn “ON” the immune response when needed.
- Other checkpoint proteins turn “OFF” the immune response to prevent an immune response that is too strong. An immune response that is too strong can harm healthy cells.

Cancer cells sometimes use checkpoint proteins to turn off an immune response. By turning off an immune response, cancer cells can avoid being attacked by the immune system.

Checkpoint inhibitors block cancer cells from turning off the immune system. When cancer cells are blocked from turning off the immune response system, the immune cells can then attack the cancer cells.

Examples of medicines that are checkpoint inhibitors include:

- atezolizumab (Tecentriq)
- avelumab (Bevancio)
- cemiplimab (Libtayo)
- durvalumab (Imfinzi)
- ipilimumab (Yervoy)
- nivolumab (Opdivo)
- pembrolizumab (Ketruda)

## **How do I receive ICI medicine?**

You will receive your ICI medicine by needle or a small tube that goes into a vein. This is called an intravenous (IV) infusion.

Your doctor may treat you with ICI alone or with other cancer treatments, such as chemotherapy. Each treatment take about 30 minutes, but could be longer depending on the type of ICI you get.

The entire treatment may last a few months or longer. How long treatment lasts depends on factors like:

- the type of cancer you have
- the type of ICI you get
- how well your body responds to the treatment
- how your cancer responds to the treatment

Sometimes, people have to stop ICI before the end of their treatment plan because:

- the treatment is not working
- they are having severe side effects

## **Do I need to have blood tests done before my ICI treatment?**

You will need to have blood tests before your ICI treatment. Ask your doctor if you can do the blood tests at a lab near your home, such as LifeLabs (recommended).

You should do your blood tests at least 1 to 2 days before your treatment day. This helps your health care team have enough time to review the results and prepare your medicine.

## What changes do I need to make while getting ICI medicine?

Below are some changes you may need to make while getting immunotherapy:

- **The amount of alcohol you drink:**

Drinking alcohol affects your liver. Immunotherapy may also affect your liver and cause it to become inflamed (swollen). If your liver is inflamed, drinking alcohol will make it worse. Talk to your oncologist before drinking alcohol. You may have to limit or stop drinking alcohol.

- **Travel plans:**

Making travel or not may depend on whether:

- your immunotherapy treatment plan allows long enough breaks between treatment for travel
- you feel well enough
- you can get travel insurance because of your treatment

If you can travel, make sure you are close to a hospital in case you have side effects that need medical treatment. You may also want to check about travel insurance, as your Ontario coverage (OHIP) is limited when you are outside of Ontario. Talk to your oncologist about any travel plans you have.

## What are the risks of having ICI treatment?

There is a small risk you may develop a reaction during the infusion of ICI treatment. ICI-related reactions happen when the immune system reacts too strongly to an unknown substance in your body. If you have an ICI-related reaction you may get one or more of these symptoms:

- rashes
- itchiness
- fever
- chills
- trouble breathing



- feeling tightness on your throat
- swelling on your tongue or lips
- drop in blood pressure (some symptoms may include feeling dizzy, lightheaded, confusion, clammy skin)
- increase in blood pressure (some symptoms may include headache, feeling dizzy, vision changes, chest pain, shortness of breath)

Most of the ICI-related reactions occur during the first treatment. A reaction can happen within minutes to hours of your ICI treatment.

### **What should I do if I have a reaction during my ICI treatment?**

Let your health care team know right away if you feel unwell during treatment. They will give you medicines (such as steroids and antihistamines) to stop the reaction. For the rest of your other immunotherapy treatments, you need to take medicines to prevent a reaction.

### **What side effects should I watch for?**

The side effects of ICI are different for each person. No one knows how many side effects you will get. Some people have no side effects at all.

When your side effects start and how long they last depend on:

- the type of cancer you have and how advanced it is
- how healthy you are before treatment
- the type of immunotherapy you get and the dose (amount)

**Important:** ICI drugs can cause inflammation (swelling) in many parts of your body. Inflammation can be very serious and even cause death. Side effects can also come back months after your treatment has stopped.



Let your health care team know **as soon as possible** of any side effects, even if they are mild or are not listed in this booklet. You need to get treatment as soon as you notice symptoms so that your health care team can help you better manage your side effects. Getting treatment early can help stop serious problems.

See page 16 for information on how to contact your health care team.

## **Will my ICI medicine affect my fertility?**

Fertility means being able to get pregnant or being able to get someone pregnant. How immunotherapy affects fertility is not known at this time since immunotherapy is a new type of treatment. At this time, it is suggested that people:

- Use effective birth control if there is any chance you can get pregnant. Immunotherapy may harm your developing baby. Birth control should be used during immunotherapy and for at least 6 months after treatment.
- Discuss future plans for children with your health care team.
- Tell your oncologist if you are pregnant. Your oncologist will talk to you about options.
- Do not breastfeed or chestfeed while getting immunotherapy. Some immunotherapy medicine may be passed to your baby through breast milk.

## The information below lists serious side effects of checkpoint inhibitors, what you should watch for and what to do.

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### Side effect: Fever, with or without chills (shaking)

#### Symptoms to watch for:

A temperature of 38.3 °C (100.9 °F) once **OR** 2 readings of 38 °C (100.4 °F) over a 1-hour period.

#### What to do

- Call your health care team or CAREPath for advice. See page 16 for contact information.
- Do not take medicine that can lower your fever, like acetaminophen (Tylenol) or ibuprofen (Advil) before you talk to your health care team.



**Go to the nearest emergency department** if you have other symptoms (for example, feeling unwell, trouble breathing, feeling dizzy, vomiting, and diarrhea).

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### Side effect: Inflammation (swelling) of the colon or bowel (Colitis)

#### Symptoms to watch for:

- Diarrhea (more than 4 loose, watery poo in a day)
- Stomach pain or cramps
- Nausea (feeling like throwing up)
- Bloating feeling in tummy
- Mucus or blood in poo

#### What to do:

- Do **NOT** take Imodium before you talk to your health care team, or unless it is prescribed by your health care team.
- Drink lots of clear fluids such as:
  - water
  - clear broths
  - juices
  - drinks that contain electrolytes (for example, Gatorade® or coconut water)

- Avoid caffeine, sugary and alcohol drinks as they can make your symptoms worse.



### **Go to the nearest emergency department if you have**

- 4 or more loose, watery poos (diarrhea) within a 24-hour period
- a fever, a temperature of 38.3 °C (100.9 °F) once, **OR** 2 readings of 38 °C (100.4 °F) over a 1 hour period)
- blood in poo or black sticky looking poo
- feeling very tired and weak

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## **Side effect: Skin reaction (Dermatitis)**

### **Symptoms to watch for:**

- Rash (flat, raised skin or bumps)
- Redness or darkness of the skin
- Dry, itchy skin

### **What to do**

- Use only skin cream or medicine that your health care team approves to treat your rash.
- Protect your skin from extreme temperature and sun.
- Use sunscreen with SPF 30 or higher.
- Seek medical help right away if you have:
  - a rash that covers more than one-third of your body. For example, your whole chest and tummy area, or an entire arm or leg
  - blisters, open sores, or peeling skin
  - severe itchiness
  - trouble swallowing or breathing

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## Side effect: Inflammation (swelling) of the lungs (Pneumonitis)

### Symptoms to watch for:

- Having difficulty breathing or catching your breath, even when you are not doing anything
- Severe chest pain that squeezes or feels crushing
- Feeling faint when you stand up

### What to do

- Call your health care team or CAREPath for advice
- Go to the nearest emergency department if you have chest pain or trouble catching your breath.

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## Side effect: Inflammation (swelling) of the liver (hepatitis)

You may not have any early symptoms of changes to your liver. Your oncologist will order blood tests to check that your liver is working properly.

### What to do

- Avoid drinking alcohol to keep your liver healthy.
- Do not take medicines that can harm your liver without talking to your health care team first. Examples of these medicines include:
  - acetaminophen (Tylenol)
  - naproxen (Aleve)
  - diclofenac (Voltaren)
  - ibuprofen (Advil)



### Go to the nearest emergency department if you have:

- Increased or worsening pain on the upper right side of the stomach
- Severe nausea (feeling like throwing up)
- Vomiting (throwing up)
- Dark or tea coloured pee

- Yellowing of the skin and white part of your eyes
- Itchiness all over your body with no rash
- Increased bleeding and bruising

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### **Side effect: Inflammation of the kidneys (Nephritis)**

You may not have any early symptoms of changes to your kidneys. Your oncologist will order blood tests to check that your kidneys are working properly.

#### **What to do**

- Talk to your pharmacy before taking over-the-counter medicines (for example, Advil, aspirin, naproxen, ibuprofen) as some of them can harm your kidneys.
- Tell your health care team if you have one or more of these:
  - Peeing too much or too little
  - Change in your pee such as dark colour, pee that seems foamy, blood in the pee, or pee that smells bad
  - Swelling in your ankles, feet, hands and face. Call your health care team as soon as you notice swelling in these areas.

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### **Side effect: Inflammation (swelling) of the brain and nerves**

#### **What to watch for**

- Headaches
- Trouble remembering things
- Feeling sleepy all the time
- Muscle weakness
- Numbness or tingling in hands and feet
- Eyes feeling sensitive to light (for example, light feels too bright)
- Constipation (trouble having a poo)

## What to do



**Go to the nearest emergency department** if you have one or more of these symptoms:

- Severe headaches or headaches that get worse
- Confusion, less alert
- Hallucinations (seeing or hearing things that are not real)
- Neck stiffness
- Rapid heart rate
- Fever
- Trouble keeping your balance and falling

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## Side effect: Hormone problems

ICI drugs can affect your glands. This can cause glands to produce too many or too few hormones. Hormones are chemicals in your body that control things such as sleep, body temperature, appetite, sex drive and much more.

### What to watch for:

Depending on the type of hormones being affected, you may have 1 or more of these symptoms:

- Headache
- Feeling tired and weak
- Weight gain or weight loss
- Dizziness or feeling faint
- Mood changes (irritable, forgetful, trouble focusing)
- Trouble falling or staying asleep
- Hair loss
- Feeling cold all the time
- Changes in vision (eye irritation like redness or itchiness, pain, blurry vision, double vision)
- Voice becomes deeper sounding
- Feeling thirsty or wanting to pee all the time

- Changes in your sexual desire and ability to have sex, for example:
  - lack of erection
  - vaginal dryness

### **What to do:**

Let your health care team know if you have any of these symptoms as soon as possible. Your oncologist can order blood tests to check your hormone level. If your levels are too low or high, your oncologist can give you medicine to bring your hormones to a normal level.



**Go to the nearest emergency department** if you have one or more of these symptoms:

- need to pee very often and are feeling thirsty
- feel very dizzy or faint
- have constant headaches or a headache that is getting worse
- feel very tired and not able to do routine activities
- have vision problems such as:
  - blurry vision
  - double vision
  - trouble seeing things outside your direct line of vision (peripheral vision)

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## **Are there any long-term effects of immunotherapy?**

Because immunotherapy is a new form of treatment, oncologists do not know what all of the long-term effects of immunotherapy are. Some people get an autoimmune condition after immunotherapy treatment.

An autoimmune condition is when your immune system attacks your healthy cells. If you get an autoimmune condition after immunotherapy treatment, you may have to take medicine to treat the condition for a long time. Ask your oncologist what the known long-term risks of treatment are.



## What happens if my immunotherapy does not work?

Learning your cancer is back or growing is hard. If your immunotherapy does not work, your oncologist may offer you:

- another type of immunotherapy
- another type of cancer treatment (for example, chemotherapy, targeted therapy, or radiation therapy)
- a chance to enroll in a clinical trial

Talk to your health care team about your goals of care and treatment options. Your goals of care will help your health care team decide your next treatments.

## How to contact your Princess Margaret health care team

<b>Monday to Friday</b> between 9:00 am to 4:00 am	Call the Princess Margaret Clinic Triage Line at _____ Someone will return your call within 2 to 4 hours.
<b>After hours</b> between 5:00 pm to 8:30 am <b>Holidays and weekends</b> Available 24 hours a day	Call CAREpath at <b>1 877 681 3057</b>

If you cannot reach your health care team and feel unwell, go to the nearest emergency department.

## Remember:

- ✓ Let the doctor and nurse at the emergency department know that you are getting immunotherapy.
- ✓ Show your immunotherapy wallet card (see the picture below) if you have one. It is also helpful to take a picture of your card on your phone so you always have it with you.

Show this card to all of your Healthcare Providers	
<p>The conditions on this card may be life-threatening for me, and must be treated urgently with instructions from my cancer care team. If I am experiencing any of these side effects, please contact my oncology team immediately. For more information, visit <a href="http://cancercaresontario.ca/immunotherapytoolkit">cancercaresontario.ca/immunotherapytoolkit</a></p> 	<p>I have an increased risk of the following autoimmune adverse events:</p> <ul style="list-style-type: none"><li>• Dermatitis</li><li>• Diarrhea/colitis</li><li>• Endocrinopathies including hyper or hypothyroidism, adrenal insufficiency or diabetes (including diabetic ketoacidosis)</li><li>• Other toxicities including: cardiac, ocular, hematological, myopathies and neurological (including paresis, Guillain-Barré and encephalitis)</li></ul>
My name is:	If I have an adverse event contact:
I take this immune checkpoint inhibitor drug:	During office hours:
My main oncologist is:	After office hours:
The doctor who prescribed me this drug is:	

- ✓ Bring your medicines in their original packages or bring an up-to-date list of medicines you take. This includes:
  - over-the-counter medicines (medicine not prescribed by a doctor)
  - vitamins or mineral supplements (for example, vitamin D)
  - herbal remedies (for example, St. John's Wort or Ginseng)

## Where can I get more information about immunotherapy?

Here are a few places you can get more information online:

### **Canadian Cancer Society**

Website: [www.cancer.ca](http://www.cancer.ca)

### **Cancer.Net: Immunotherapy - an Introduction**

Website: <https://www.cancer.net/navigating-cancer-care/vidoes/treatments-tests-and-procedures/immunohterapy-introduction>

### **National Cancer Institute: Immunotherapy to Treat Cancer**

Website: <https://www.cancer.gov/about-cancer/treatment/types/immunotherapy>

### **Society for Immunotherapy of Cancer (SITC) Connected Patient Resources**

Website: <https://www.sitcancer.org/connectedold/p/patient>

The development of patient education resources is supported by the Princess Margaret Cancer Foundation.



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