

# Immunotherapy and the Side Effects

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## In this booklet, you will learn about:

- Immunotherapy
- How immunotherapy works
- Side effects of immunotherapy
- Immunotherapy at the Odette Cancer Centre
- What to do in an emergency





**This booklet will tell you when to call your healthcare team if you feel unwell during your treatment.**

**This is how to contact your healthcare team:**

- 1** Monday to Friday between 9:00am - 4:30pm call **416-480-5000** or the phone number given to you by your nurse: \_\_\_\_\_
- 2** On weekdays between 4:30pm and 8:30am and 24 hours a day on weekends and holidays call the After hours Symptom Management Telephone Line at **1-877-681-3057**.

Let the nurse know:

1. Your oncologist's name: \_\_\_\_\_
2. Your cancer type: \_\_\_\_\_
3. You are having immunotherapy and the treatment name: \_\_\_\_\_
4. Your symptom(s)

**If you cannot reach your healthcare team and feel very unwell go to your nearest emergency department.**

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# What is immunotherapy?

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Immunotherapy is a type of cancer treatment (drug) that uses your body's own immune system to fight cancer cells. Your immune system fights infections and diseases.

## How does immunotherapy work?

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Immunotherapy makes your immune system stronger at fighting cancer cells. Your immune system becomes better at finding and attacking cancer cells.

Immunotherapy can continue to fight your cancer even after your treatment ends. This can sometimes lead to long-term control of your cancer.

# What is the difference between immunotherapy and chemotherapy?

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Chemotherapy attacks cancer cells directly by stopping their growth and spread. Chemotherapy can also affect healthy or normal cells. This can cause side effects like hair loss, mouth sores, or nausea.

Chemotherapy and immunotherapy often have different side effects because they work in different ways. Immunotherapy can also affect normal cells and cause immune-related side effects. This booklet will teach you more about these side effects, and how you can work with your healthcare team to manage them.

## When is immunotherapy used to treat cancer?

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Immunotherapy treatments are given to some people with melanoma, lung cancer, kidney cancer and head and neck cancers. It is also given to some people with other cancers as part of clinical trials (research studies) at the Odette Cancer Centre.

Your medical oncologist (cancer doctor) will give you advice about what type of medication (drug) is best to treat your cancer. This depends on many things like the type of cancer, stage of cancer, other treatments you have had, and your overall health.

# What will happen when your doctor recommends immunotherapy for your cancer?

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- 1** You and your medical oncologist (cancer doctor) will talk and make a decision about when to start immunotherapy.
- 2** Your doctor will give you information about the treatment. You will be asked to sign a consent form agreeing to the treatment and that you understand the benefits and side effects.
- 3** You will be called with the appointment date for your first treatment. You may be asked to come in for a blood test either a few days before the treatment day or on the same day.

# What are the symptoms and side effects of immunotherapy?

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Many of the side effects from immunotherapy drugs are because the immune system is more active. This can cause inflammation (swelling) of tissues in the body, like the bowel, thyroid, lung, or liver.



## **Important:**

**Some side effects of immunotherapy can be dangerous if they are not managed quickly and correctly. The following pages will tell you what to do for each symptom. Please follow the directions carefully.**

## How to contact your healthcare team:



- 1 Monday to Friday between 9:00am - 4:30pm call **416-480-5000** or the phone number given to you by your nurse: \_\_\_\_\_
- 2 On weekdays between 4:30pm and 8:30am and 24 hours a day on weekends and holidays call the After hours Symptom Management Telephone Line at **1-877-681-3057**.

Let the nurse know:

1. Your oncologist's name: \_\_\_\_\_
2. Your cancer type: \_\_\_\_\_
3. You are having immunotherapy and the treatment name: \_\_\_\_\_
4. Your symptom(s)

**If you cannot reach your healthcare team and feel very unwell go to your nearest emergency department.**



# 1 Fever



## What is a fever?

A fever is a temperature reading in the ear or mouth of:

- 38.3°C (100.9°F) once OR
- 2 readings of at least 38°C (100.4°F) taken over a 1 hour period.

It is best to take your temperature using a digital thermometer in the ear or mouth. Do not drink or eat anything cold or hot before you take your temperature.

What to look for:	What to do:
<p>If you feel unwell use a digital thermometer in your ear or mouth to find out if you have a fever.</p>	<ul style="list-style-type: none"><li>• <b>Take any medications (drugs) as advised to you by your healthcare team for fever. For example, Tylenol® (acetaminophen).</b></li><li>• <b>If your fever does not go down, you have other symptoms, and/or you feel really unwell, call your healthcare team to report your symptoms. If you do not hear back from your healthcare team within 2 hours, go to your nearest emergency room.</b></li></ul>

## 2 Flu-like symptoms



### What is it?

Some patients will get flu-like symptoms from their immunotherapy injection. The most common is feeling warm and having body aches (like you have the flu).

What to look for:	What to do:
<ul style="list-style-type: none"><li>• Feeling warm, with or without a fever</li><li>• Aches and pains</li><li>• Chills (feeling like you are cold and cannot get warm)</li></ul>	<p><b>If your symptoms last more than 48 hours, call your healthcare team to report your symptoms.</b></p>

### 3 Pneumonitis (breathing problems)



#### What is it?

Pneumonitis is inflammation (swelling and irritation) of the lungs.

What to look for:	What to do:
<ul style="list-style-type: none"><li>• Trouble breathing/ catching your breath</li><li>• New or worsening cough</li><li>• Chest pain</li><li>• Any of the symptoms above and a fever</li></ul>	<p><b>Call your healthcare team to report your symptoms. If you do not hear back from your healthcare team within 2 hours, go to your nearest emergency department.</b></p>

## 4 Diarrhea and colitis



### What is it?

Diarrhea is loose, watery bowel movements (going poo) or more bowel movements than what is normal for you. If it is severe, it may be a sign of inflammation (swelling) in the colon, called colitis.

What to look for:	What to do:
<ul style="list-style-type: none"><li>• 1 or 2 loose, watery bowel movements</li></ul>	<ul style="list-style-type: none"><li>• <b>Take any medications (drugs) your healthcare team has told you to take for diarrhea. For example, Imodium® (loperamide).</b></li><li>• <b>Call your healthcare team to report your symptoms.</b></li><li>• <b>Watch closely for the more serious symptoms like fever, blood in your poo and stomach pains that feel like cramps.</b></li></ul>
<ul style="list-style-type: none"><li>• More than 3-4 bowel movements in a 24 hour period, especially if you also have:<ul style="list-style-type: none"><li>• Fever</li><li>• Blood in your poo</li><li>• Stomach pains that feel like cramps</li></ul></li></ul>	<ul style="list-style-type: none"><li>• <b>Do NOT take Imodium® (loperamide).</b></li><li>• <b>Call your healthcare team to report your symptoms. If you do not hear back from your healthcare team within 2 hour, go to your nearest emergency department.</b></li></ul>

## **Other things you can do that may help:**

- If you have diarrhea it is important to drink lots of clear liquids like water, clear juice or clear broth so that you do not get dehydrated. Avoid drinks with lots of sugar, caffeine, or alcohol as they can cause dehydration.
- If your bottom is sore after you have a lot of diarrhea, try a sitz bath – a warm soothing soak to clean your skin and lower the risk of infection. Ask your healthcare team how to do this.

## 5 Fatigue



### What is it?

Fatigue is a common side effect for people with cancer. The feeling of fatigue is more than just feeling tired, and does not always go away after a good night's sleep. For some people the fatigue can be caused by the cancer itself or from cancer treatments like immunotherapy medications (drugs).

What to look for:	What to do:
<ul style="list-style-type: none"><li>• Feeling tired after doing normal activities like taking a shower, climbing the stairs or cooking</li><li>• Still not feeling rested after a good night's sleep</li><li>• Your fatigue is not getting better or is getting worse</li></ul>	<ul style="list-style-type: none"><li>• <b>Tell your healthcare team at your next appointment, or call your healthcare team to report your symptom if your appointment is more than 2-3 weeks away.</b></li><li>• <b>If you feel so tired that you cannot get out of bed, especially if it lasts more than 1 day, call your healthcare team to report your symptoms.</b></li></ul>

## **Other things you can do that may help:**

- It might sound funny, but exercise is one of the best things you can do to fight cancer-related fatigue. Try to do light to moderate exercise like walking, swimming, or yoga. Your goal should be 30 minutes of exercise a day. If 30 minutes is too difficult to do all at once, try 5-10 minutes a couple of times a day.
- A healthy and balanced diet will help with your energy. Be aware of the foods you eat. Cook or make meals when you have the most energy.
- At the Odette Cancer Centre, there are registered dietitians that are free and part of your healthcare team. You can connect to nutrition services by visiting the Nutrition Centre (T-Wing ground floor, TG-261 beside the East Elevators). Call us at 416-480-5000 ext. 3438.
- Talk to your healthcare team, especially the nurses. They can give you other tips to help fight fatigue.

## 6 Skin rash



### What is it?

Some patients on immunotherapy will have a skin rash or dry, itchy, very uncomfortable skin.

What to look for:	What to do:
<ul style="list-style-type: none"><li>• Skin rash</li><li>• Redness or darkness of the skin</li><li>• Dry and/or itchy skin</li><li>• Bumps</li><li>• Blisters or peeling skin</li><li>• Other changes to your skin</li></ul>	<ul style="list-style-type: none"><li>• <b>Use any medications already suggested to you by your healthcare team to manage your skin.</b></li><li>• <b>Call your healthcare team to report a rash or skin changes that get worse.</b></li></ul>

### Other things you can do that may help:

- Protect your skin from the sun with a sunscreen that has an SPF of 30 or higher.
- Wear a hat if you are going outside to protect your face from the sun.
- Try to avoid the heat or extreme cold.
- Talk to your healthcare team about a calming moisturizer cream that you can use on your skin. Your doctor may prescribe a steroid cream to heal your rash, or medication (drug) such as an antihistamine to help with any itch.



## 7 Changes in your hormones

### What is it?

Hormones control many things in your body, like energy, weight, body temperature, sleep, and more. Immunotherapy can change the levels of some of these hormones.

Your doctor will order blood tests to check your hormone levels while you are on immunotherapy.

What to look for:	What to do:
<ul style="list-style-type: none"><li>• A need to pee more than usual</li><li>• Dizziness</li><li>• Feeling faint</li><li>• Muscle aches</li><li>• Hair loss</li><li>• Rapid heartbeat</li><li>• Persistent headache</li><li>• Unexpected weight changes</li><li>• Extreme fatigue (tiredness)</li></ul>	<p><b>Call your healthcare team to report your symptoms. If your symptoms get worse and you do not hear back from your healthcare team within 2 hours, go to your nearest emergency department.</b></p>

## 8 Changes to your liver

### What is it?

Immunotherapy might make your liver larger or swollen (inflamed). There are medications that can help with this. Often there are no symptoms when your liver changes, and they will only be seen on the blood tests your doctor orders.

What to look for:	What to do:
<ul style="list-style-type: none"><li>• The white part of your eyes looks yellow</li><li>• Your skin is a grayish-yellow</li><li>• Very dark urine (pee)</li><li>• Itchy skin without a visible rash</li><li>• Extreme tiredness</li><li>• Pain on the right side of your belly</li></ul>	<p><b>Call your healthcare team to report your symptoms. If you do not hear back from your healthcare team within 2 hours, go to your nearest emergency department.</b></p>

### Other things you can do that may help:

- Like many medications, immunotherapy drugs can affect your liver. It is best not to drink alcohol while on these drugs. Talk to your healthcare team if you do drink alcohol.

## 9 Vitiligo

### What is it?

Vitiligo is changes to the colour or texture of your skin.

<b>What to look for:</b>	<b>What to do:</b>
<ul style="list-style-type: none"><li>• Changes to the colour of your skin, usually white or lighter patches</li><li>• Changes to the colour and thickness of your hair, eyelashes, eyebrows and facial hair</li></ul>	<p><b>Tell your healthcare team about your symptoms at your next appointment.</b></p>

## 10 Sexual and pregnancy related questions



### What is it?

Cancer and cancer treatments like immunotherapy can affect how you feel mentally and physically about your body and about sex.

Some people get a lower libido (loss of the desire to have sex).

### Important:

**Talk to your doctor or nurse if you have questions about fertility (getting pregnant) now or in the future. We are here to help you.**

**Many cancer treatments are not safe for people who are pregnant. If you or your partner can get pregnant you must use birth control while on immunotherapy.**

**Condoms are recommended because they will also protect your partner's skin from any irritation from contact during sex.**

## 11 Other side effects

There are other rare side effects that can affect your eyes, nerves, brain, or heart. Your healthcare team will help you monitor for these.

**If you notice anything new about your body or with your health that you are not sure about, ask your healthcare team if it may be related to your treatment or your cancer.**

# Vaccines and immunotherapy

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It is important to talk to your healthcare team if you are thinking about getting any vaccines for health or travel. Some vaccines may make you sick when you are on immunotherapy or once finished your treatment.



Talk to your doctor about getting any vaccines **including the flu shot**.

## **Important:**

**Do not have live vaccines 42 days or less before your treatment. You will not be able to have live vaccines at any point after your immunotherapy treatment has ended.**

Examples of live vaccines include: measles, mumps, rubella, chicken pox, shingles, yellow fever, rabies, BCG (vaccine for Tuberculosis), and typhoid (oral) vaccine. Nasal spray flu vaccines (e.g. Flu-Mist) are not allowed.

If you think you have had a live vaccine less than 42 days before your immunotherapy treatment please tell your doctor and nurse.

# Immunotherapy at the Odette Cancer Centre

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Immunotherapy drugs are given by I.V. (intravenous – directly into your vein) at the chemotherapy unit at the Odette Cancer Centre.

Our chemotherapy nurses are trained to treat you with immunotherapy. Both immunotherapy and chemotherapy are monitored by medical oncologists, prepared for you by our cancer-trained pharmacists, and given to you during your day of treatment by our chemotherapy nursing team.

# What to do in an emergency

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Some side effects of immunotherapy can be very dangerous if not managed quickly and correctly. **If you go to the emergency department while on immunotherapy, please remember the following:**

- Tell the nurse or doctor at the emergency department that you are getting immunotherapy.
- Show the nurse and doctor your hospital emergency wallet card, if given to you with this booklet.
- Bring all your medications (drugs) in their original packaging, or an up-to-date list of all your medications (drugs), and show it to the nurse or doctor at the emergency department.
- Tell the nurse or doctor that:
  - You are a patient of Dr. \_\_\_\_\_ at Sunnybrook Hospital and if needed, the doctor can be reached through the locating line **416-480-4244**.
  - You are receiving immunotherapy drug(s):  
\_\_\_\_\_  
\_\_\_\_\_
  - For cancer type: \_\_\_\_\_

**Odette Cancer Centre**  
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Toronto, Ontario M4N 3M5  
[sunnybrook.ca/programs/occ](http://sunnybrook.ca/programs/occ)

