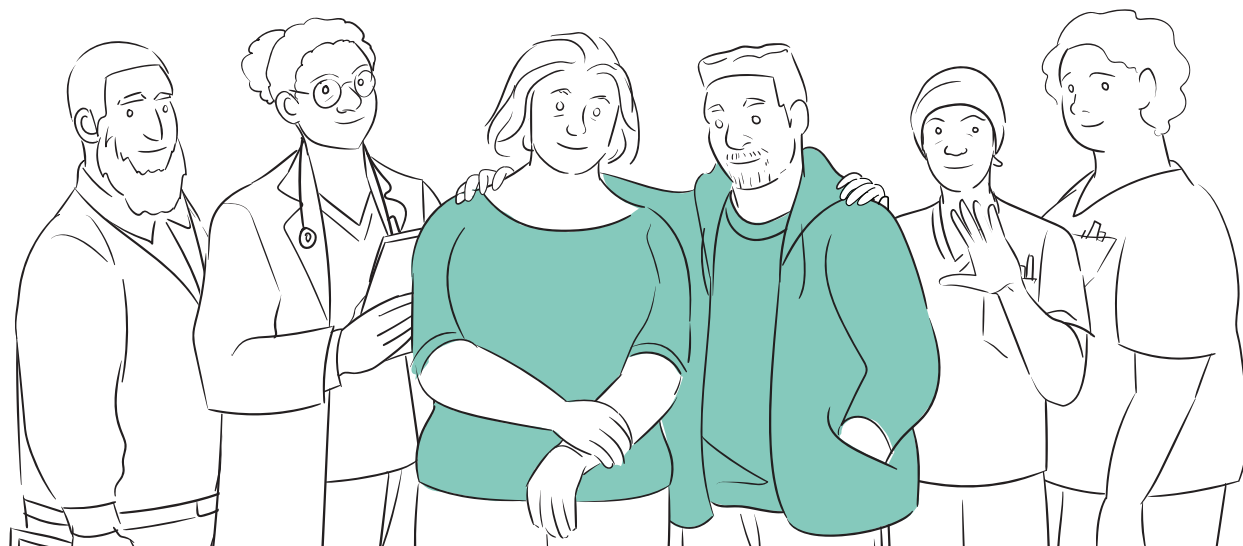


A patient's guide to **Immuno-Oncology**



Things you may want to know about cancer immunotherapy

This guide is a starting point to help you understand:

- **How immunotherapy works in your body**
- **What your immunotherapy experience may be like**
- **What help and support is available to you throughout your journey**

After reading this guide, we hope that you will feel more comfortable:

- **Playing an active role in your treatment**
- **Having open and honest conversations with your care team**
- **Explaining immunotherapy to your loved ones**

Introduction

What is immuno-oncology?

You may already know about some of the treatment options available for cancer, such as surgery, chemotherapy, radiation, or targeted therapy.

With advances in science, there's now another way to treat certain cancers: **immuno-oncology (I-O)**, sometimes known as **cancer immunotherapy**, or just **immunotherapy**.

'Immuno' in immunotherapy refers to your immune system. Immunotherapy uses drugs that **may help your body's own immune system fight cancer**.

Who is on my care team?

Your care team is dedicated to helping you through your journey. You can lean on them for support with any part of your experience with immuno-oncology.

Your care team is every type of doctor, nurse, or healthcare professional who touches your care. It is also your friends, family, and caregivers.

Ask your oncologist who is on your care team.

Your care team may include:

- Your **oncologists**, your **primary care physician (PCP)**, your **surgeon**, and any other **specialists** that you see
- **Nurses, treatment navigators** (sometimes called nurse or patient navigators), **pharmacists**, or **dietitians**
- **Social workers, counselors, therapists, psychiatrists, insurance or financial advisors**
- **Caregivers, friends, support groups, or spiritual advisors**
- and **more**



What's in this guide?

PART 1: The story of Immuno-Oncology 4

- **A garden analogy to help you understand immunotherapy**
- **The immune system and cancer**
- **Immunotherapy as a treatment option**
- **Possible effects of immunotherapy**

PART 2: Your experience through cancer 27

- **Your journey through treatment**
- **Understanding cancer survivorship**
- **Emotional well-being**
- **Talking to your care team and learning more**

In this guide, we've provided space for you to take notes and write down your questions. **Keep this guide for your reference and consider bringing it to your appointments.**

PART 1

The story of Immuno-Oncology

Sections of Part 1:

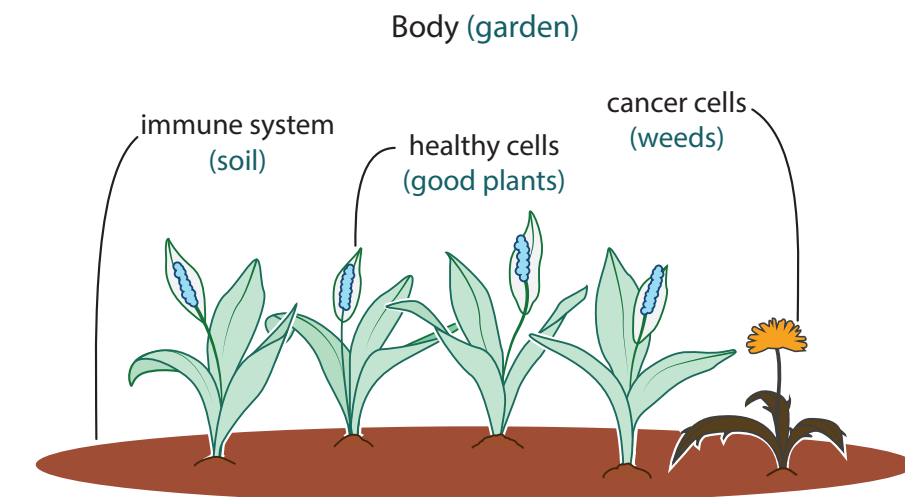
A garden analogy to help you understand immunotherapy	5
The immune system and cancer	11
Immunotherapy as a treatment option	15
Possible effects of immunotherapy	20

A garden analogy to help you understand immunotherapy

The following pages will introduce you to immunotherapy as a type of cancer treatment. We will use an analogy of your body as a garden to explain how immunotherapy works, and how it is different from other treatments.

The following pages will answer these questions:

- **How might immunotherapy work with my immune system to fight cancer?**
- **How is immunotherapy different from other types of cancer treatment?**
- **What is a biomarker test and what does it have to do with treatment options?**

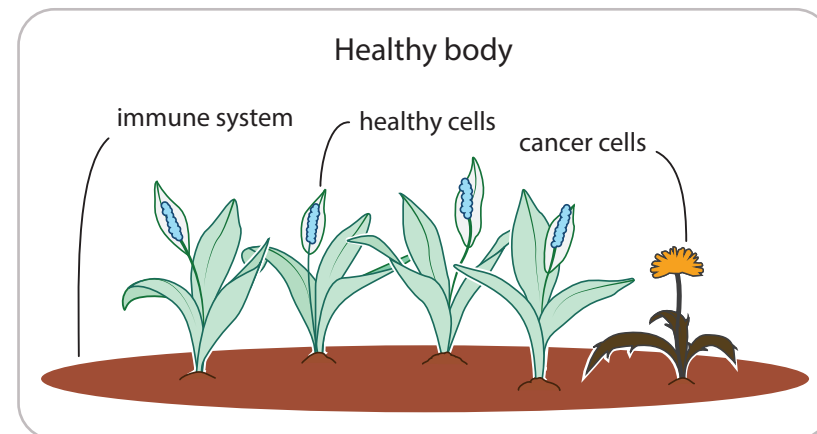


How might immunotherapy work with my immune system to fight cancer?

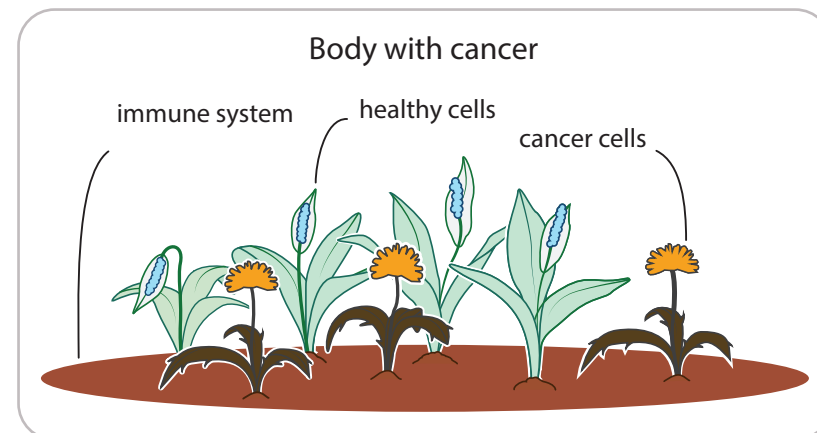
Immunotherapy may help your body's own immune system fight cancer.

Here is an analogy to explain the concept.

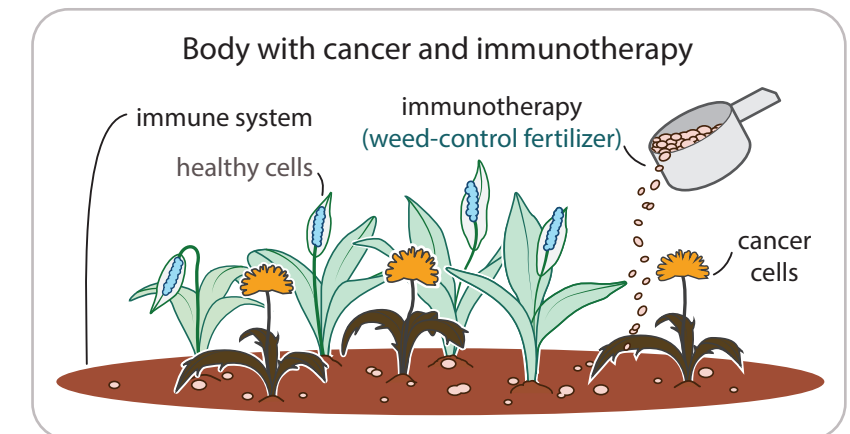
Imagine your body as a garden, where the soil is your immune system. When you're healthy, the soil is rich and well tended, and the garden is green. Normally, the soil is able to prevent weeds from growing out of control.



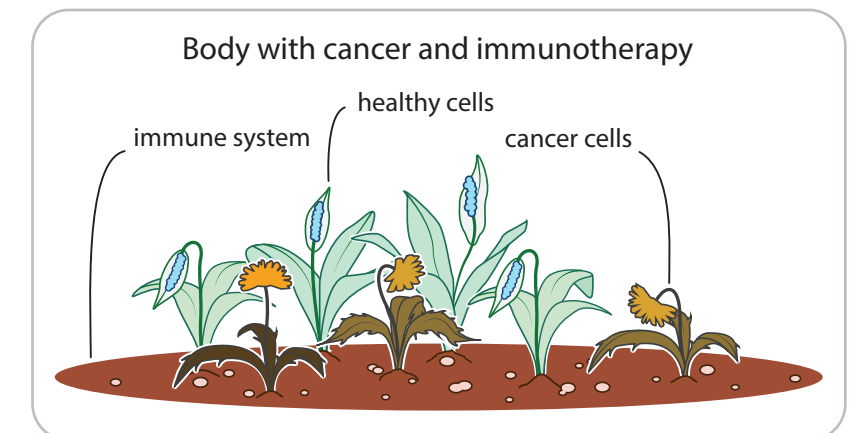
Cancer cells are like weeds in your garden. Sometimes, the soil can allow weeds to grow and spread, and soon, the entire garden suffers as your plants compete for space and nutrients.



Immunotherapy is like adding weed-control fertilizer to the soil. It enriches the garden's existing soil.



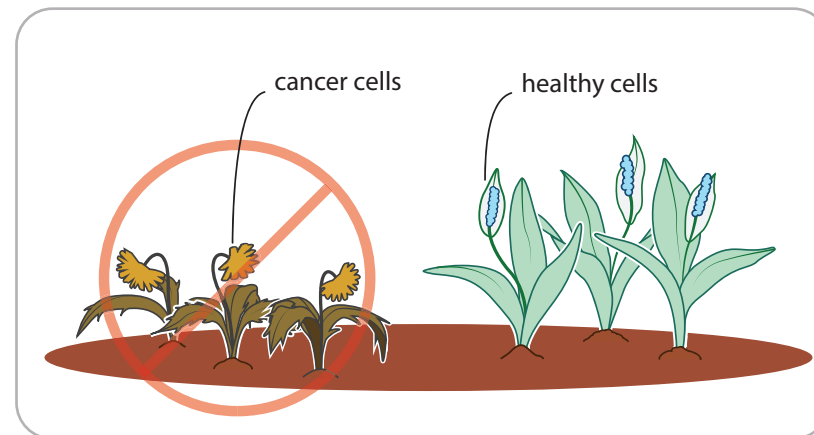
Now the soil can help keep the weeds under control and can maintain the garden's health. But too much fertilizer may harm your garden.



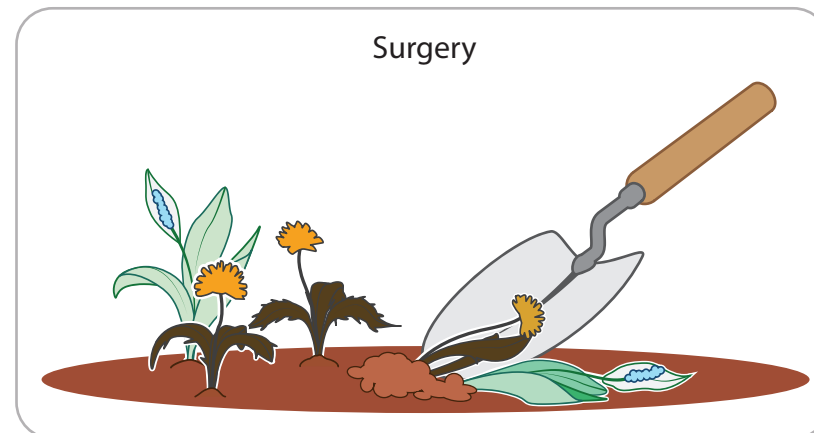
How is immunotherapy different from other types of cancer treatment?

Immunotherapy is a unique approach that may **help your body's own immune system fight cancer**. To understand how immunotherapy is different from other types of cancer treatment, let's continue with the garden analogy.

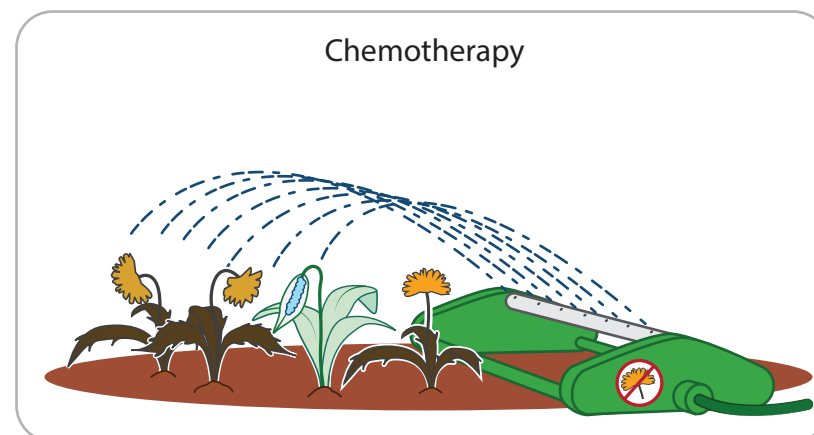
If your body is like a garden, you and your care team will decide **how to remove the weeds** (cancer cells) **while doing the smallest amount of harm to the good plants** (healthy cells).



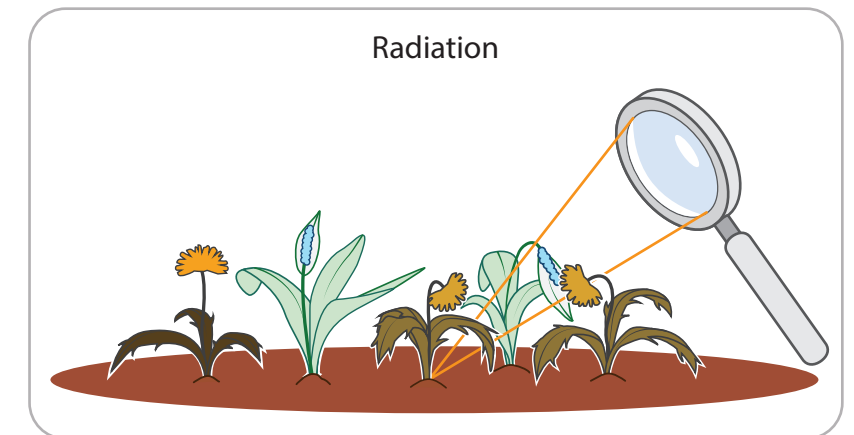
Surgery removes large patches of weeds and the soil around them, sometimes disturbing the good plants and leaving some weed roots behind.



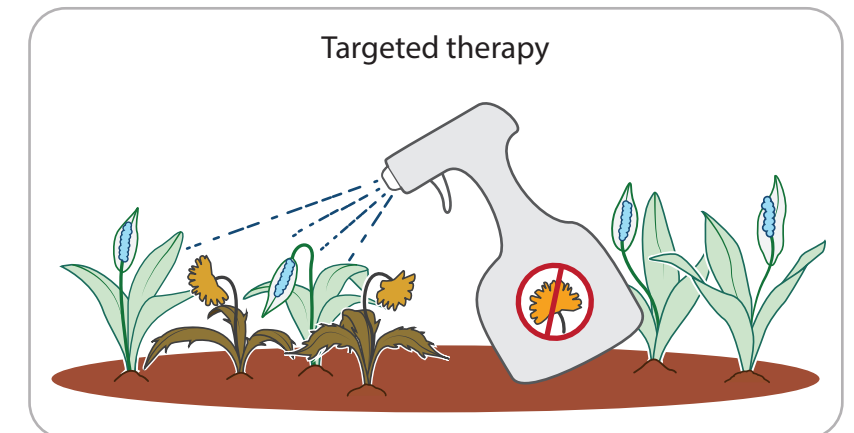
Chemotherapy is like spraying a general weed killer on the whole garden. This approach may not kill all the weeds, and may also harm some good plants.



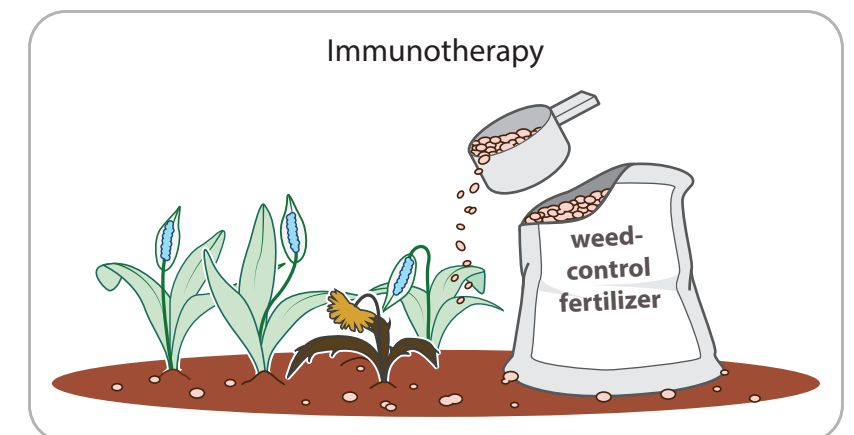
Radiation is like increasing the power of the sun with a magnifying glass to target and dry out the weeds, but in the process, some of the good plants can also be harmed.



With **targeted therapy**, weeds are directly sprayed with weed killer. Good plants may still be harmed.



Instead of targeting the weeds, **immunotherapy** is like adding a weed-control fertilizer to the soil. This fertilizer enriches the soil to help control weeds, which in turn restores the health of your garden. But too much fertilizer in the soil might harm your garden.



Ask your care team about the different treatment options available to you.

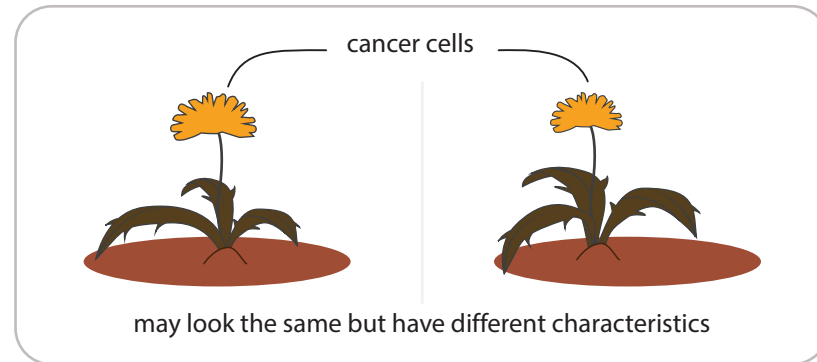
What is a biomarker test, and what does it have to do with my treatment options?

Your care team may order several tests throughout your cancer treatment to better understand your cancer. Some of these tests are known as **biomarker tests**.

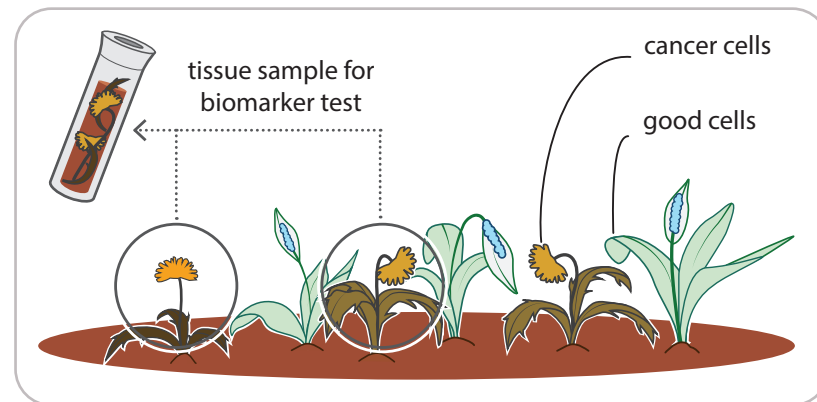
Testing for specific biomarkers may help guide treatment decisions by providing you and your care team with information about how your body is responding to **treatment now**, and may respond to a **potential treatment later**.

Depending on the cancer you have, your care team may mention biomarkers when talking about any cancer treatment options. To understand how biomarkers may be used, let's continue with the garden analogy.

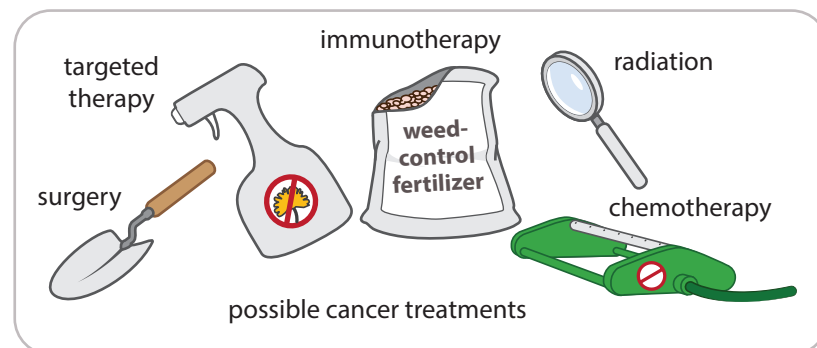
Every person's garden may have different types of weeds. And even if those weeds look the same, they each have their own unique characteristics which would change the way a gardener might go about removing them.



One way to help choose what to use to remove a particular weed is to take a closer look. Getting a biomarker test could be like taking a few pieces of your weeds out of your garden to take a look at them more closely.



The test results may help you and your care team understand more about your garden and how to try controlling the weeds.



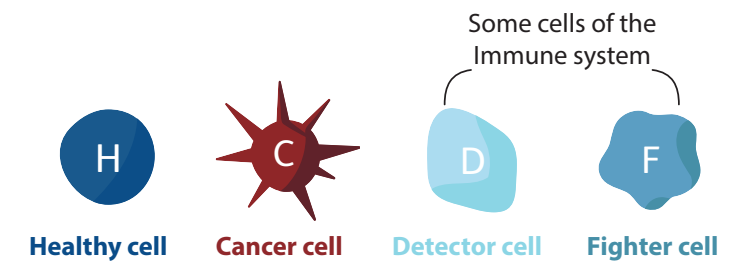
The immune system and cancer

The following pages will answer these questions:

- **What is the role of the immune system?**
- **How can the immune system be "tricked" by cancer?**

Cell guide

Look for these key players as you read on:

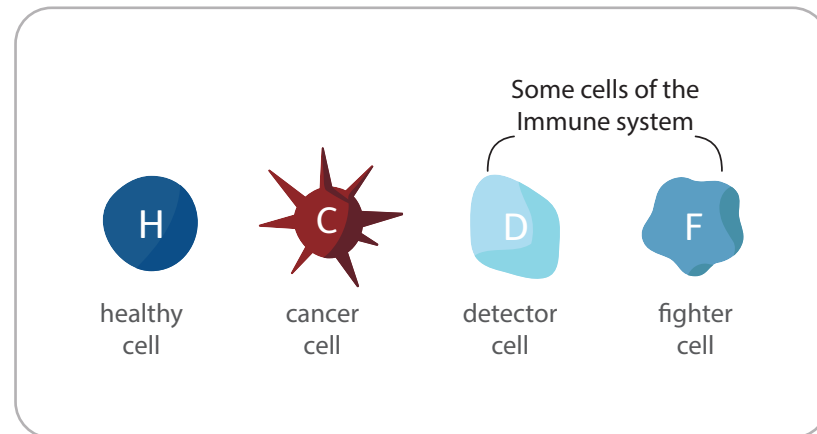


What is the role of the immune system?

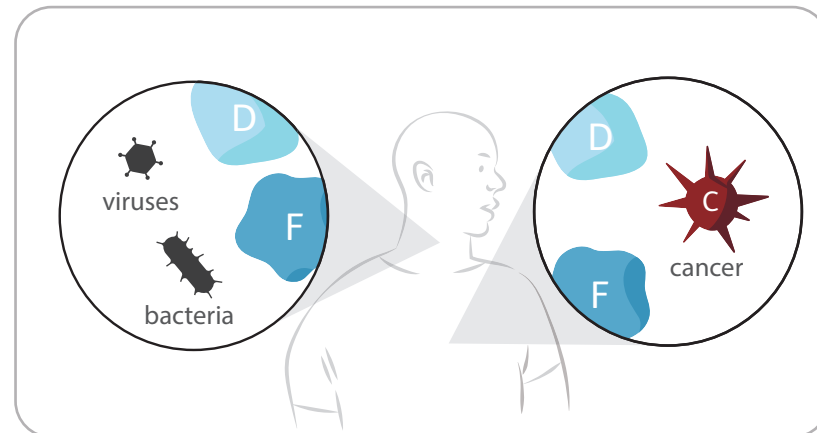
Your immune system can protect healthy cells from infections and diseases, and can prevent unhealthy cells from growing out of control. Let's take a closer look.

Normally, you have different **healthy cells** in your body. In some cases, there may be unhealthy cells, like **cancer cells**.

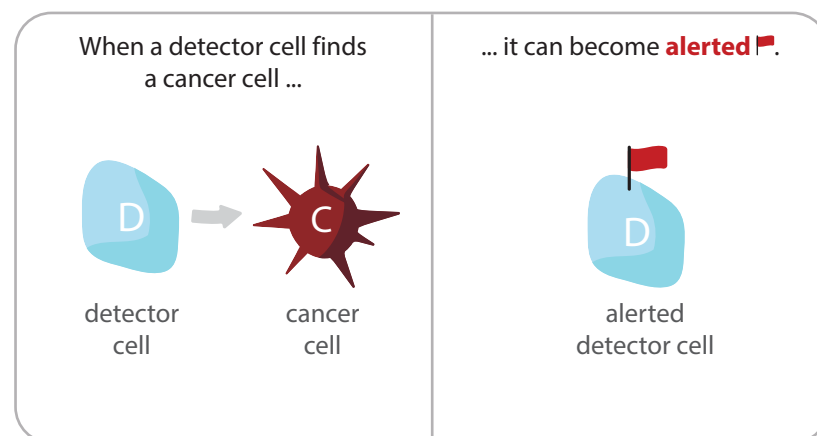
Your **immune system** is made up of many types of cells, including: **detector cells** and **fighter cells**.



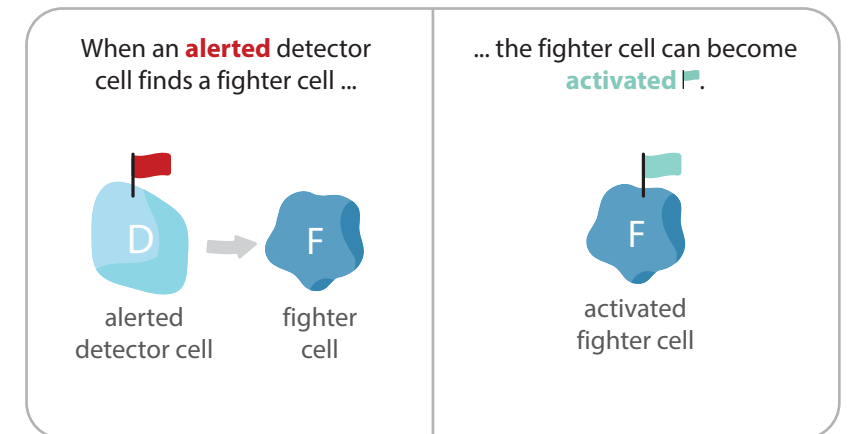
Detector cells and fighter cells travel around your whole body looking for threats from outside of your body like **viruses** and **bacteria**, and threats inside your body such as **cancer**.



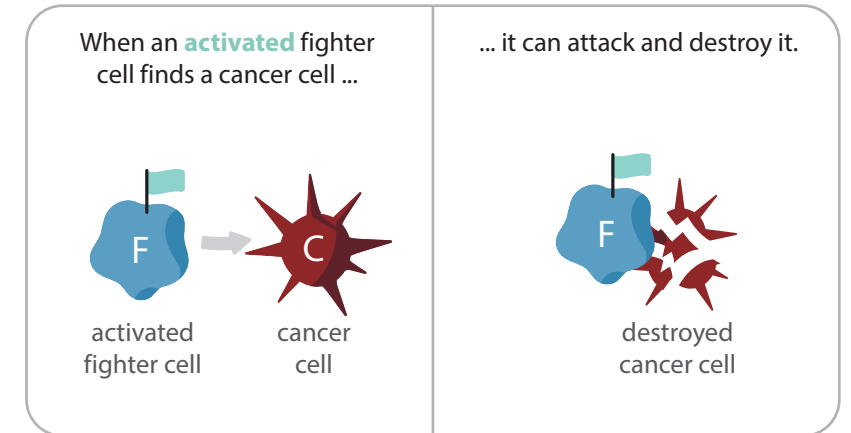
Normally, when detector cells find threats — like cancer cells — they can become **alerted**.



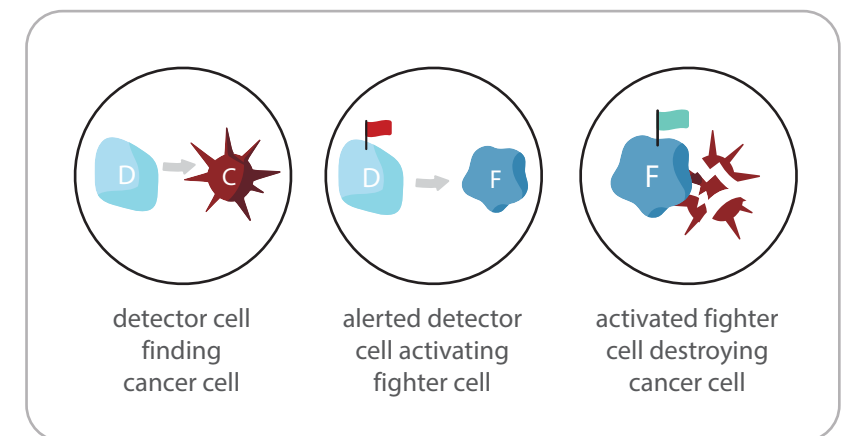
Alerted detector cells seek out fighter cells for help. When found, the **fighter cells can become activated**.



Activated fighter cells can then seek out, find, attack, and destroy cancer cells.



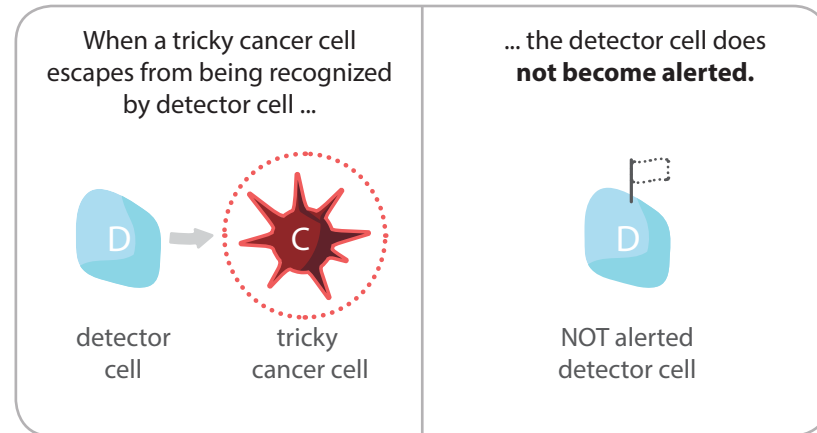
Through these interactions, the immune system can work to keep your body healthy. **This is happening in your body all the time.**



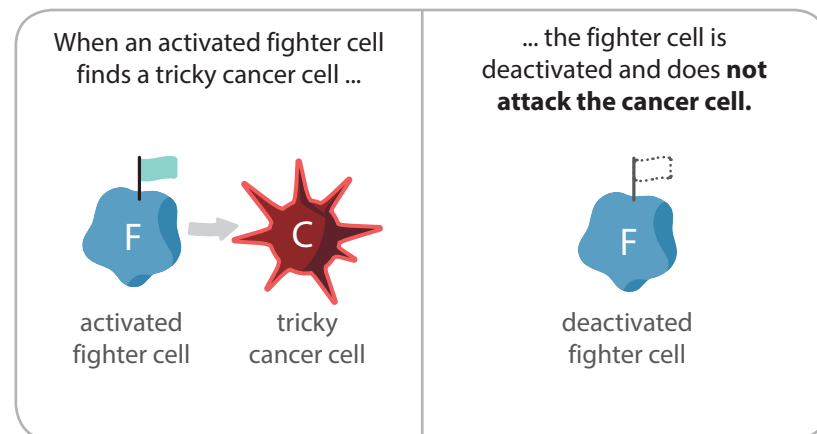
How can the immune system be “tricked” by cancer?

Your immune system can be tricked by cancer cells. Cancer cells can change the way immune cells normally react to cancer. Let’s take a closer look.

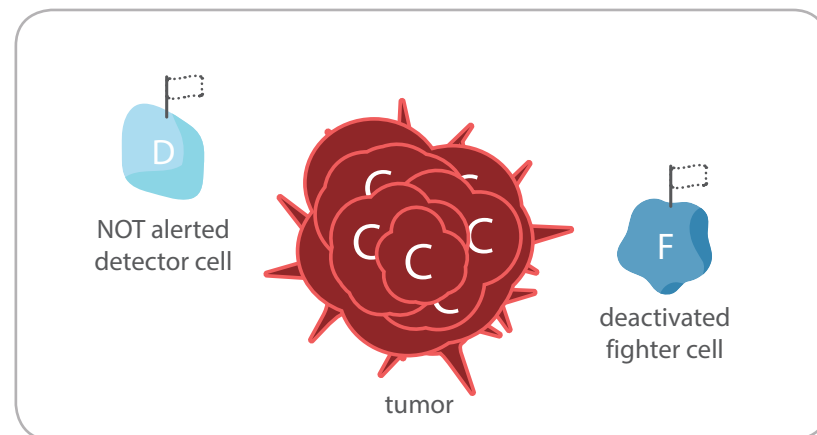
Tricky cancer cells can escape from being recognized by detector cells. In turn, the detector cells do not become alerted.



Fighter cells can be deactivated by tricky cancer cells, and in turn do not attack cancer cells.



Over time, tricky cancer cells that can **escape from detector cells** and **deactivate fighter cells** can continue to survive and grow into a tumor.



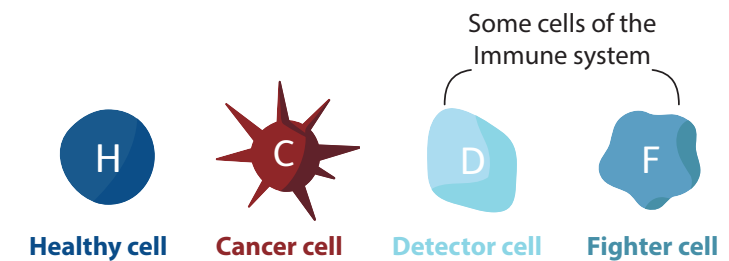
Immunotherapy as a treatment option

The following pages will answer these questions:

- How might immunotherapy help the immune system fight cancer?
- What might happen if I receive immunotherapy with another cancer treatment?

Cell guide

Look for these key players as you read on:

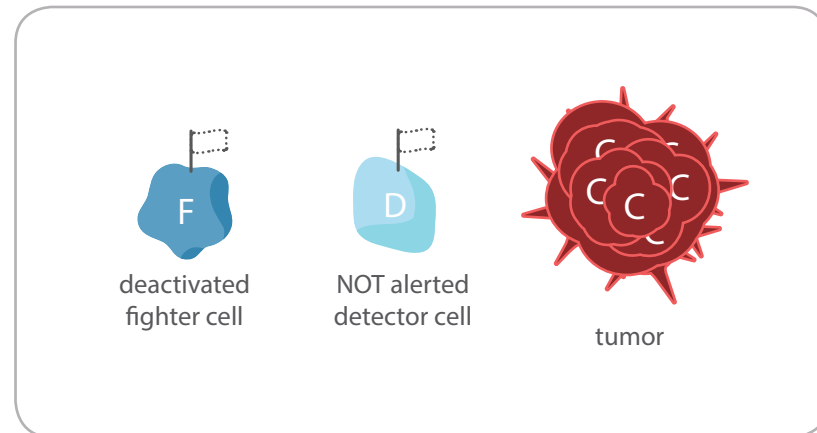


How might immunotherapy help the immune system fight cancer?

There are different types of immunotherapies. They can all help the immune system in different ways. Let's take a closer look.

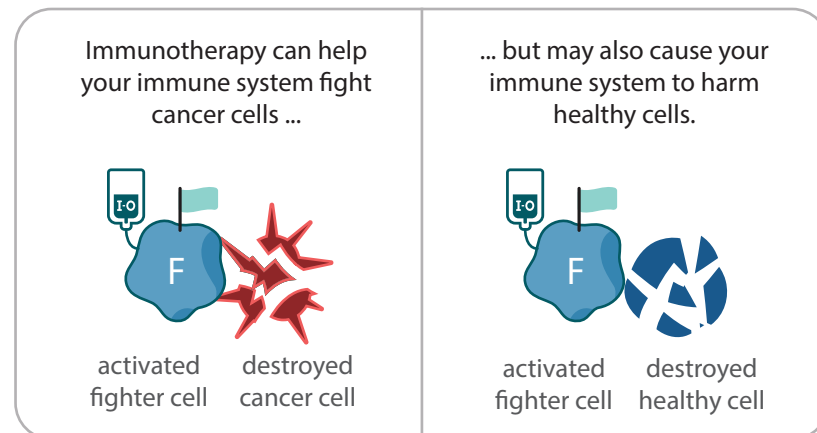
Tricky cancer cells can **escape from detector cells** and **deactivate fighter cells**. In turn, these cancer cells can continue to survive and grow into a tumor.

Your immune system **may need help finding and attacking the tricky cancer cells again.**

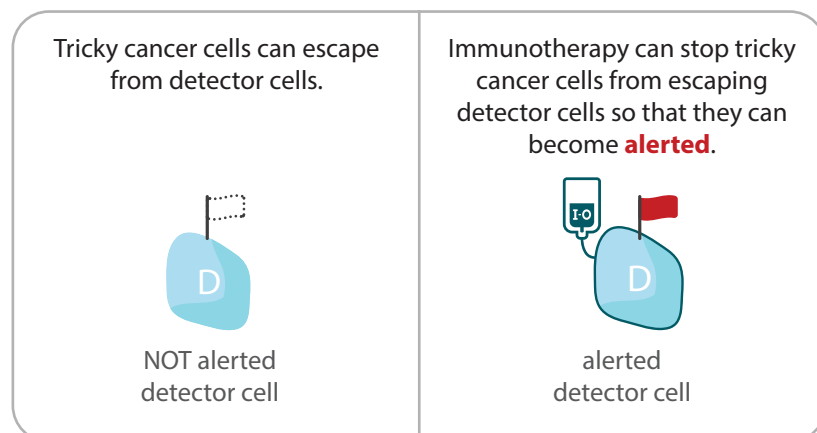


That's where immunotherapy comes in.

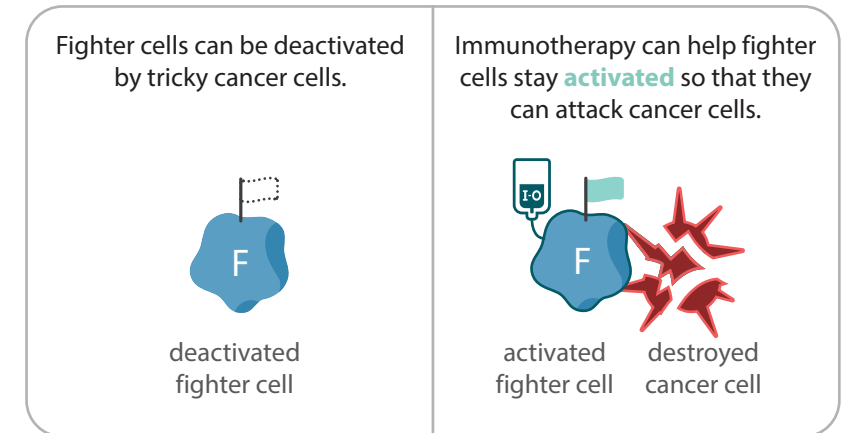
Immunotherapy can help your **immune system** fight cancer cells. However, immunotherapy might also cause your immune system to harm healthy cells.



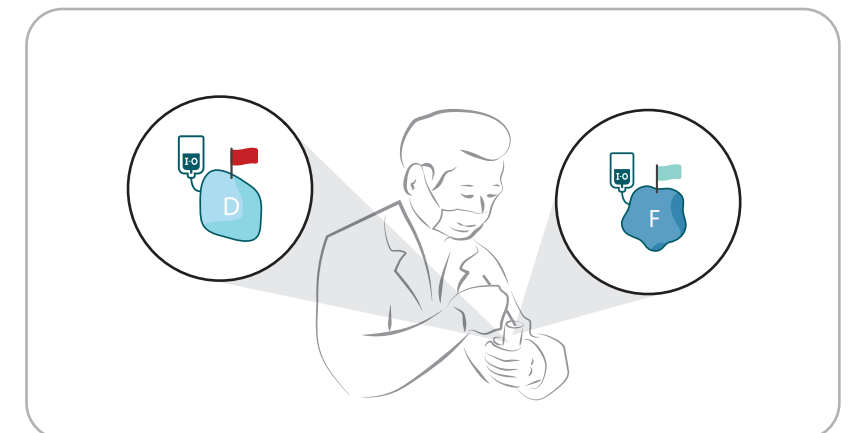
Some immunotherapies help detector cells stop tricky cancer cells from escaping. Then, detector cells can become **alerted**.



Other immunotherapies can **help fighter cells stay activated**. The activated fighter cells can then attack cancer cells.



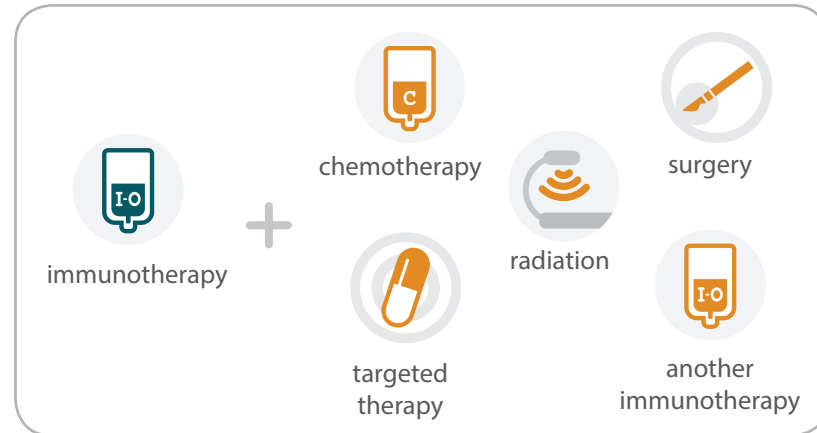
There is research being done to see how new immunotherapies may help your immune system fight cancer.



What might happen if I receive immunotherapy with another cancer treatment?

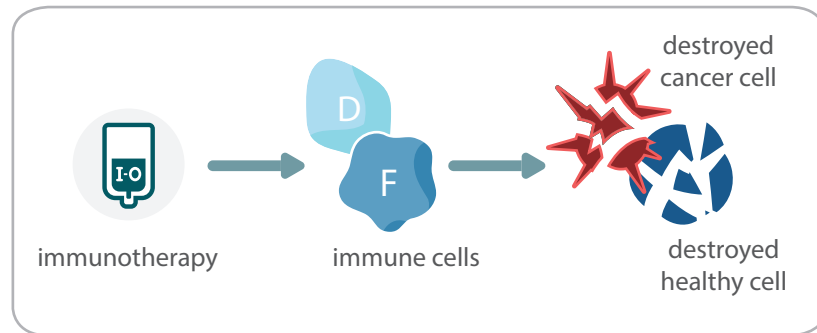
There is ongoing research into how immunotherapies can be used with other treatments to fight cancer. Generally, **when you take more than one cancer treatment, both the risks and benefits may be increased.**

Immunotherapy can be used together with other treatments, like chemotherapy, radiation, surgery, targeted therapy, and another immunotherapy.



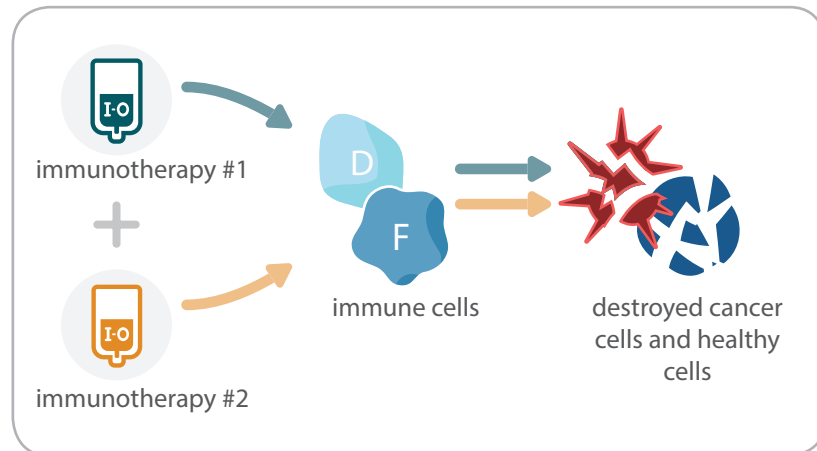
One immunotherapy:

Taking one type of immunotherapy treatment can help your immune system fight cancer. But, it can also harm healthy cells in the process.



Two different types of immunotherapies together:

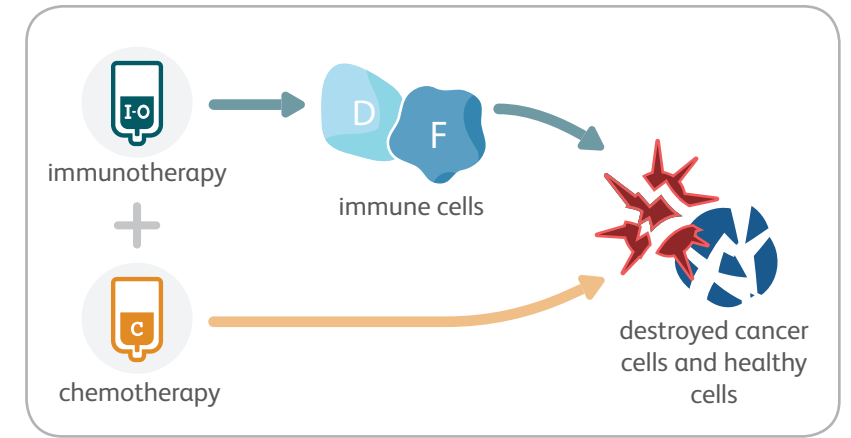
If you take two different types of immunotherapies together, there may be a **greater chance your immune cells will attack cancer.** There may also be a **greater chance of harming healthy cells.**



Immunotherapy with chemotherapy:

The idea is similar when immunotherapy is used with another type of cancer treatment.

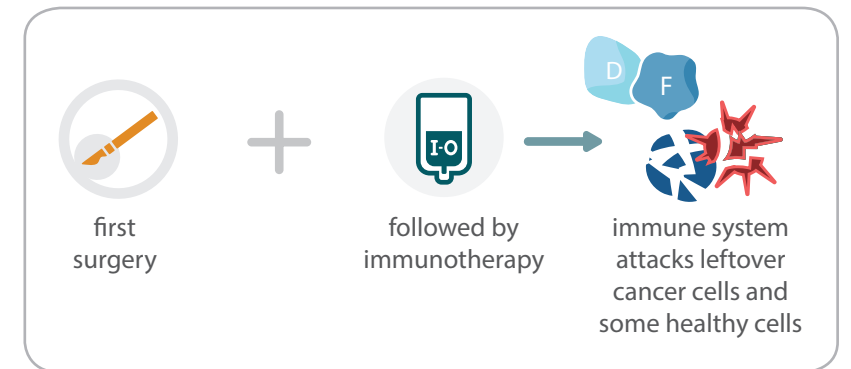
There may be a **greater chance of fighting cancer,** but also a **greater chance of harming healthy cells.**



Immunotherapy with surgery:

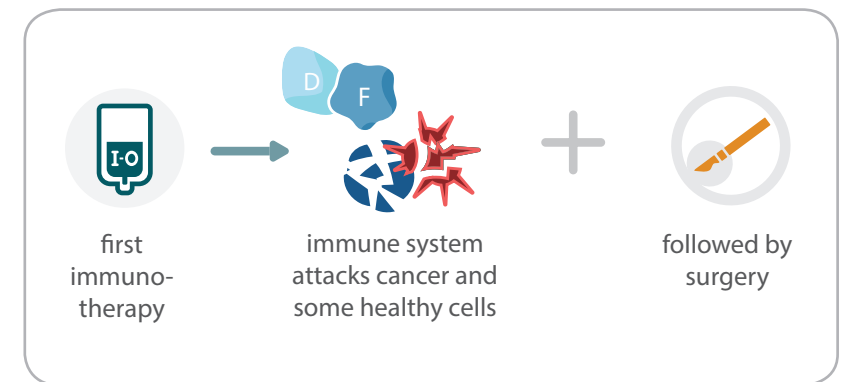
Your doctor may recommend **immunotherapy and surgery to be used one right after the other.**


Surgery may be the first treatment, followed by immunotherapy to help your immune system attack leftover cancer cells that may have been missed during surgery. You may hear this called “adjuvant” therapy.



Immunotherapy can be the first treatment to help the immune system attack cancer and make the tumor smaller. **Surgery will follow.** You may hear this called “neoadjuvant” therapy.

You may even have surgery **around** immunotherapy treatments. Your doctor may call this “perioperative” therapy.



 **Talk to your care team** about the best treatment option for you.

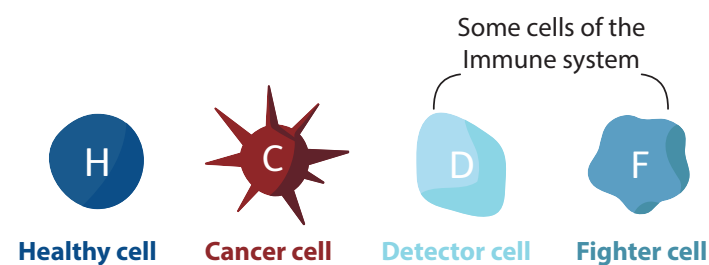
Possible effects of immunotherapy

The following pages will answer these questions:

- How might my tumor respond to immunotherapy?
- Can immunotherapy cause side effects?
- What are some possible side effects of immunotherapy?
- What should I do if I have side effects?

Cell guide

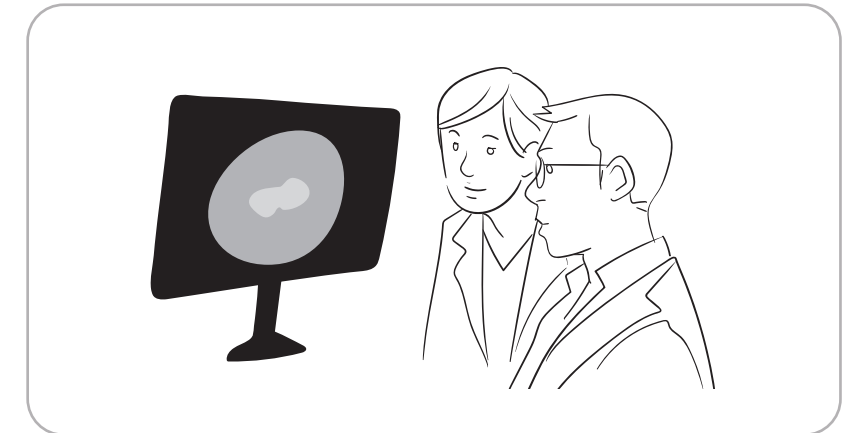
Look for these key players as you read on:



How might my tumor respond to immunotherapy?

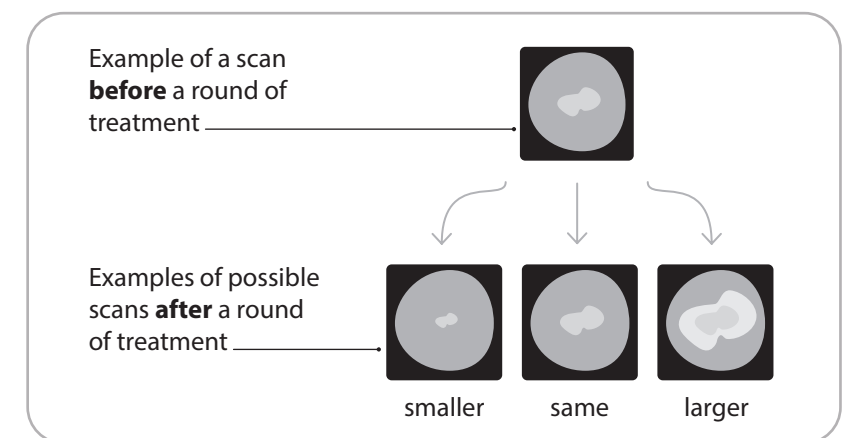
Tumors can respond differently to immunotherapy depending on the type of immunotherapy and how your immune system reacts to it. For some people, immunotherapy can help shrink the tumor. For others, the tumor may stop growing even if it does not get smaller. It is also possible that the tumor may not respond to immunotherapy at all.

At your hospital or clinic visits, your care team may use scans to monitor your progress.



After a round of immunotherapy treatment, the tumor may look **smaller, the same, or larger** compared to before.

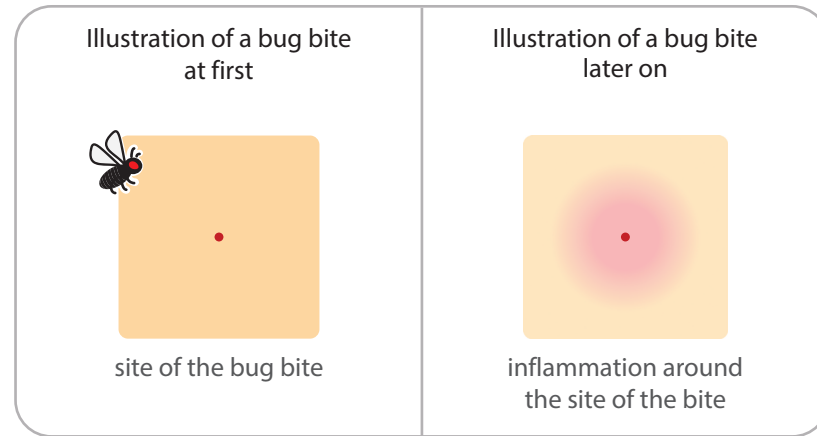
If your tumor looks larger in the scans, it may not mean that immunotherapy isn't working.



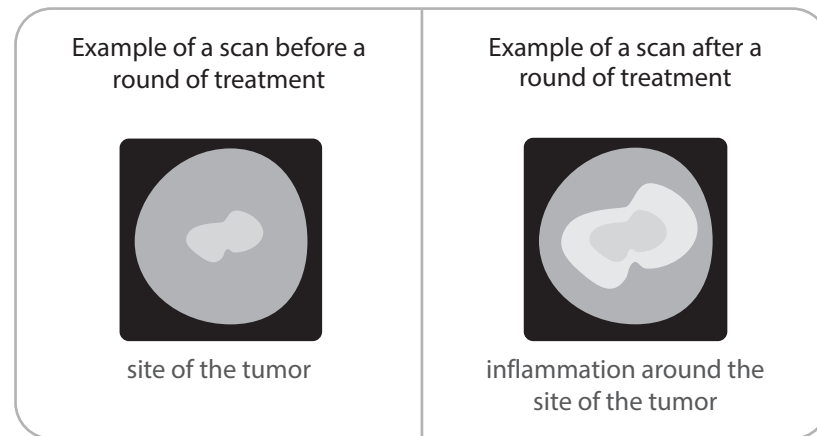
For some people who have **surgery first and then immunotherapy**, the scans may look different from the images above.

Here is an analogy to explain why this could happen.

Think of a bug bite, where the skin becomes red, hot, and swollen around the site of the bite. This is a sign of **inflammation**, which results from your **immune system's reaction to a threat, not from the bite itself**.



A similar thing could appear in your scans. If the immunotherapy is working, **inflammation may happen around the tumor** as your immune system moves to surround it. This can make your tumor look larger on scans.



In other cases when the tumor appears larger on scans, it might be that immunotherapy isn't working and the tumor is growing. **Everyone responds to immunotherapy differently.**

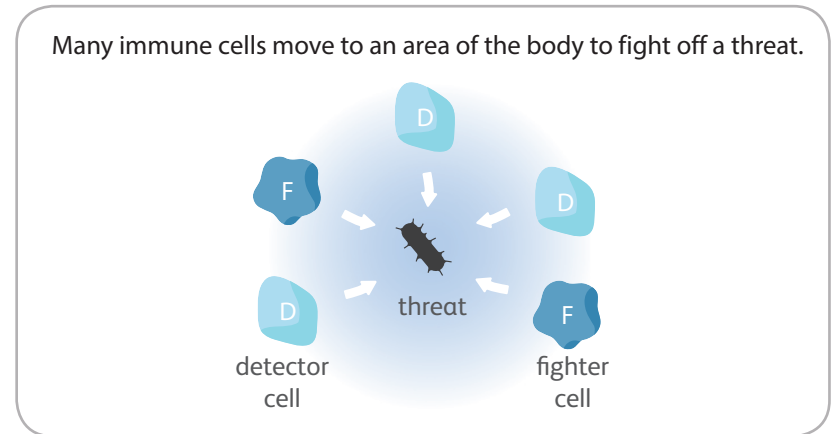
Scans are not the only way to see if immunotherapy is working. **Your care team will also be looking at other lab results and your overall well-being.**



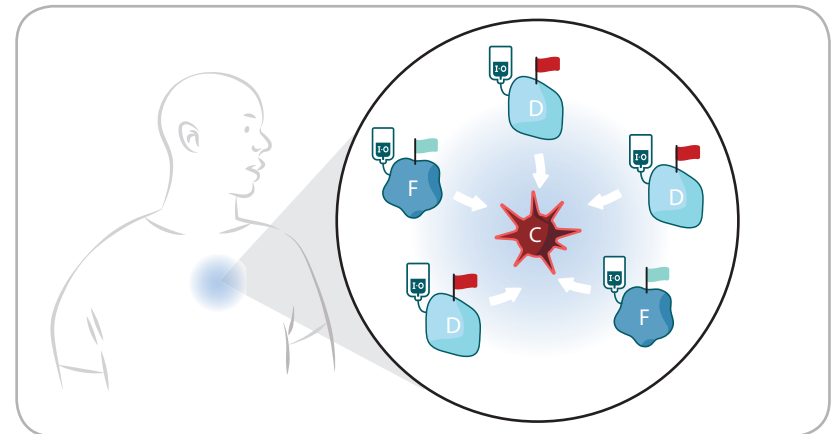
How does immunotherapy cause side effects?

Side effects can happen because the immunotherapy may cause inflammation in the body **beyond the area of the tumor**. Some side effects can become serious or life-threatening.

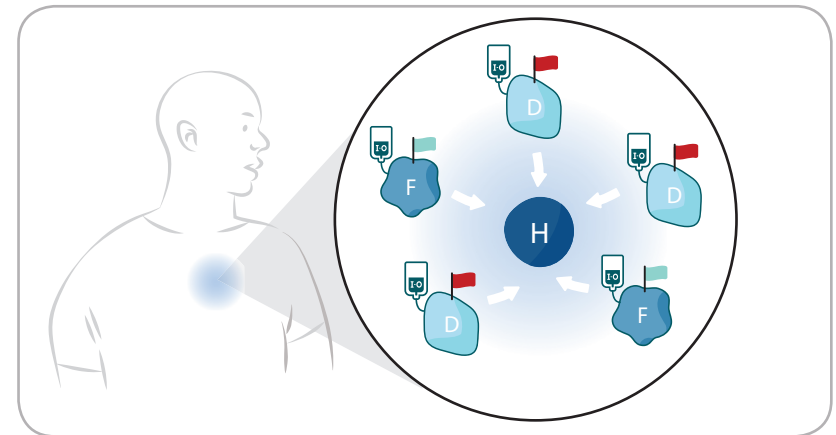
Inflammation happens when many different immune cells move to an injured or threatened area of the body to fight off the threat.



Immunotherapy can help your immune cells **attack cancer cells**. This can cause inflammation around the tumor.



However, immunotherapy can also cause your immune cells to **attack healthy cells**. This may lead to inflammation around a healthy body part.



Immunotherapy works on the immune cells that are found throughout your whole body. For this reason, inflammation may happen anywhere in your body. It may also happen at any time during or after treatment.

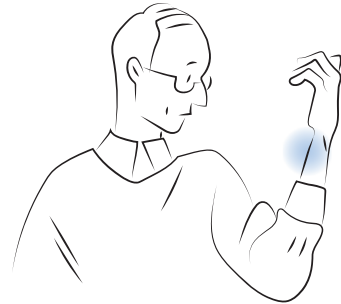
Immunotherapy works on the immune cells that are found throughout your whole body. For this reason, inflammation may happen anywhere in your body.



Inflammation looks and feels different depending on where it is in the body.

You may be familiar with inflammation of the skin, which looks like swelling and redness. But those are not the only signs. For example, inflammation of the lungs may feel more like a cough.

Inflammation of the skin may look like swelling or redness.



Inflammation of the lungs may feel like a cough.



Inflammation is not the only cause of side effects of immunotherapy.

Some side effects of immunotherapy can also be serious or life-threatening. Some side effects **may start during or even after treatment is done.**

Telling your care team about any changes you experience will make it easier for them to help.



Remember to keep track of all changes to your body, regardless of how long ago you were treated.

What are some possible side effects of immunotherapy?

Your care team will have a better idea of what side effects you may experience. **Ask your care team for a list of side effects so that you can recognize them as soon as they come up.**

The side effects that you may get will depend on the treatment combination you are receiving, and how your immune system reacts to it. Everyone's experience with immunotherapy side effects will be different.

Remember, **side effects can happen anytime during or after immunotherapy.** These side effects may happen anywhere in the body, and some may be serious, life-threatening, and life-long.



Your care team can give you a list of possible side effects for your specific immunotherapy. Talk with your care team about the kind of resources you can use to understand possible side effects with immunotherapy.

What should I do if I have side effects?

It is important to keep your care team up-to-date on how you feel. Tell your care team about any changes that are **new, different, or bothersome.** Keep close track of your symptoms, and if you have a caregiver helping you, tell them about it too.



You know your body the best, and you can tell when you are feeling good or bad.

It may help to keep a record of symptoms as they come up, so that you can **share them with your care team.**

Here are some tips on how you can identify, keep track of, and report your side effects:

- Find a way of tracking that works best for you, such as a journal
- Note how you feel after an immunotherapy treatment visit
- Let your care team know if you feel any changes that are new, different, or bothersome
- **Tell your care team about side effects as soon as possible! This may help them manage your side effects earlier.**



I notice some patients are reluctant to report side effects to their care team. My advice would be **“Do not hesitate!”** We are here to help you, and we need to be fully informed to provide the best care possible.

Tracking your side effects is key to monitoring your progress.

My doctor has always told me to remember three things about side effects:

Identify side effects:

Ask my care team for a list of side effects for my specific immunotherapy.

Keep track of side effects:

Find a personal way to keep track of what I am experiencing on paper or digitally. And get help from my caregiver if I need it.

Tell my care team:

Do not hesitate!



PART 2

Your experience through cancer

Sections of Part 2:

Your journey through treatment 28

Understanding cancer survivorship 36

Emotional well-being 40

Talking to your care team and learning more 44

Your journey through treatment

The following pages will answer questions that relate to your journey before, during, and after treatment.

Before treatment:

- **What factors are important for me to consider before starting immunotherapy?**
- **Where can I learn more about immunotherapy as an option?**

During treatment:

- **What could my immunotherapy treatment journey be like?**
- **How do I prepare for treatment visits?**
- **TELEMEDICINE** (includes four questions)

After treatment:

- **What will my journey be after I am finished with my treatment?**

What factors are important for me to consider before starting immunotherapy?

You may want to consider some of the following factors:

- What kind of **support from friends and family** will I need to help me through this treatment?
- How will I **get to the hospital or clinic** for my treatment visits?
- Will I be able to **take time off work** if I need to?
- How can I continue to **take part in activities** that are important to me?
- Will I be able to **pay for this treatment?**

Talk to your care team about any hesitation that you may have with starting immunotherapy. **It is important to have real and honest conversations with your care team about factors that are important to you.**

Where can I learn more about immunotherapy as an option?

Your care team is your best source of information. They can:

- Answer your **questions about immunotherapy**
- Recommend **trustworthy educational resources**



When I was researching treatments online, I felt pretty overwhelmed. It was hard to tell which resources were genuine, so I talked to my doctor, and she helped me find resources that were right for me.

What could my immunotherapy treatment journey be like?

Going on immunotherapy is a big decision that you will make together with your care team. Your immunotherapy journey will be unique. Keep in mind that immunotherapy may not work for everyone.

The general steps of an immunotherapy journey may be:

1. Considering immunotherapy as a treatment

- **Talk to your doctor about immunotherapy**, and how it may be different from your other cancer treatment options
- Think about important **life factors** such as cost, travel, and time commitment
- Think about whether you will be willing to:
 - **Talk to your care team** about all of your side effects
 - **Keep your care team up-to-date** and informed about your health
 - **Be an active partner** with your care team throughout your immunotherapy treatment

If you and your doctor decide that immunotherapy is the right option for you, then you will go on to steps 2 and 3.

2. Being an active partner in your treatment

- **Attend** all of your immunotherapy treatment visits
- **Tell your care team about how you feel**, including things that may be new, different, or bothersome
- **Have medical tests done** to monitor your progress and your possible side effects

3. Monitoring your health

- **Keep track of your overall health and well-being, including any side effects**
- Talk with the people around you about the **kind of help that you may need**

My doctor and I are a team. When we first discussed immunotherapy, we talked about side effects, life factors, and tests that had to happen before I even decided to get the treatment.



How do I prepare for treatment visits?

Consider doing the things listed below before going to your treatment visit.

- **Call ahead to confirm the appointment.** Ask what you might **need to bring**, or what you may need to do to prepare
- **Arrange transportation** to and from the visit
- **Write down any questions** that you might have, and any topics that you may want to discuss with your care team (like anything new, different, or bothersome)
- **Keep your health information** in one place and bring it to every visit
- **Bring something to do** while waiting for or while receiving your immunotherapy treatment infusions
- **Bring back-up** — a friend or family member who can act as a second set of ears and eyes at an appointment



Sometimes, when I get home after my appointment, I remember other things I wanted to ask. I should have written them down!

I took my laptop, books, knitting, music, even a movie to watch — just things to take my mind off the infusion.



What is telemedicine?

Telemedicine is when you and your doctor see and talk with each other using a computer, tablet, or smartphone. It may also include communicating with your care team through texts, direct messages, or online health records.

Over the years, telemedicine has become more common to overcome barriers to visits. It can be useful at every stage of the journey, from diagnosis, through treatment, and for visits after you have finished your cancer care.


What is possible to do over telemedicine?

You can do many of the same things during a telemedicine visit as when you are in person, sitting together with a doctor or your care team, including parts of the physical exam.

On a telemedicine call your care team can:

- **See** what you look like, and see any swelling or redness
- **Hear** if you're coughing or having a hard time breathing
- **Share** your scans over email or computer screen
- **Provide** emotional support, and more

Your care team can also teach you how to take your own heartbeat, blood pressure, and temperature with your home devices. They can show you how to do other parts of the physical exam too.

 **Tell your care team** what you or your caregiver may be comfortable with learning to do on the call.

What are some advantages of telemedicine?

Telemedicine may allow you to:

- Feel **more relaxed** when you are in your own home
- **Show the doctor how you do your daily activities**
- Have your **caregiver, family, or friends join** a telemedicine call even if they live far away
- **Not have to travel anywhere**, especially if you have many appointments
- **Not worry about childcare** when both parents need to attend appointments
- Be seen over a telemedicine appointment for **urgent concerns**
- Use telemedicine for **introductory visits** before you decide which doctor is the right fit for you
- Ask your care team **questions between visits**
- **See your scans** as they become available
- Be more active in your care by **learning to do some parts of the physical exam** yourself

Many patients don't even know that telemedicine is an option for them. Some patients worry that it will be hard to figure out how to use technology. Others worry that without the physical exam the doctor might miss something.



Talk to your care team about the pluses and minuses of telemedicine and any of your concerns.



How do I prepare for telemedicine visits?

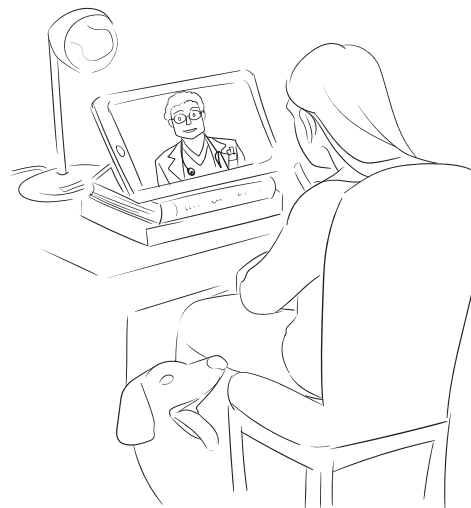
It's important to have a good set-up in preparation for the telemedicine visit. The better prepared you are, the smoother the visit will go. It may be helpful to speak with your care team about preparing for telemedicine visits when you are confirming your appointment.

Consider doing the things listed below a few days before your telemedicine visit:

- **Asking your care team what devices you may need.** You may even be able to borrow a device from your care team
- **Asking your care team what technology you may need to download,** and if your device will work with the application that you need to use for the telemedicine call
- **Asking your care team to arrange for a translator** to join the call if you need one
- **Writing down any questions** that you might have, and any topics that you may want to discuss so you don't have to worry about remembering them while you are on the call
- **Inviting a caregiver, family member, or friend to join the call** even if they are far away. Some caregivers can help with technology and position the camera to show side effects that you may not be able to do yourself

For the best set-up, find a small area of your home that is quiet and private so you can focus on talking with your doctor. Here is a useful checklist for your home set-up:

- Be in a **well lit area.** You can also have a flashlight ready
- Put the **camera as close as you can to eye level**
- Wear **loose clothes** to show any side effects
- When you use a **phone or tablet, prop it up on books** so your hands are free
- Have your **questions, notes, and a pen** handy
- Sit in a **stable chair**



What will my journey be after I am finished with my treatment?

Everyone's journey after treatment will be different. Here are some things that may become important to you after you finish your treatment.



I am now focused on being a husband again. I don't want my wife to keep thinking of me as a patient. I feel like I have leftover energy from the few years of treatment. I am working on getting my life back and re-introducing myself to my friends.

For my treatment, I had surgery and then immunotherapy right after. Later, when I saw my primary care physician for a general check-up, I was the one who had to explain the immunotherapy journey to him. This empowered me to share my story with others.



Even four years after my treatment, I continue to feel anxious every time I have to come in for follow-up scans. I connect with support groups online, and we help each other through these feelings that we call "scanxiety."

I have been finished with treatment for many years, but I still have long-term side effects. I continue to track my side effects and I tell my doctor about them right away.



It has always been important for me to tell my story of going through immunotherapy treatment. I am now a patient advocate and my wife speaks about her experience as a caregiver.

Understanding cancer survivorship

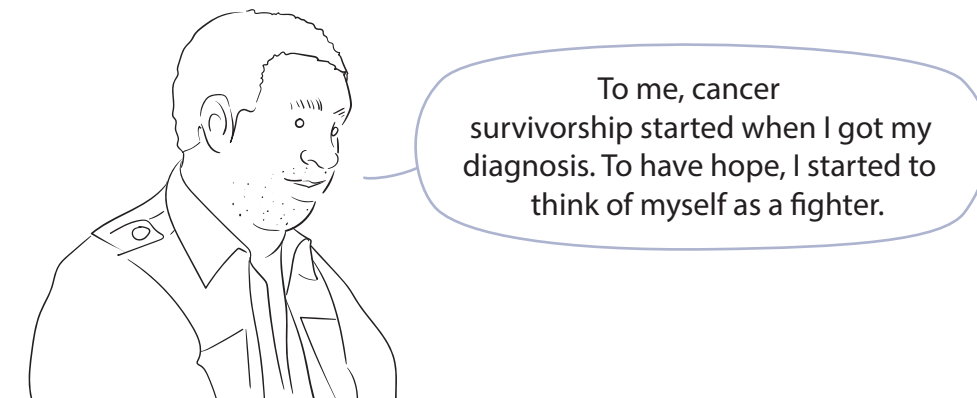
The following pages will answer these questions:

- **What is cancer survivorship?**
- **What are the elements of cancer survivorship?**
- **What is a survivorship care plan?**
- **Why do I need a survivorship care plan?**

What is cancer survivorship?

The process of living with, through, and beyond cancer, from diagnosis, treatment, and into follow-up is often referred to as “cancer survivorship.” People with cancer are living longer than they did in the past, and have new and different needs now.

Many people living with cancer now see themselves as fighters and survivors.



To me, cancer survivorship was figuring out how to live through immunotherapy treatment *and* be a dad.



To me, cancer survivorship was not suffering in silence but understanding how I could get help for how I was feeling.

Take a moment to think about what **cancer survivorship may mean to you.**

What are the elements of cancer survivorship?

Each person living with cancer is unique and has different needs and challenges along their cancer survivorship journey.

Cancer survivorship can have many elements that are important in your life. **Some will matter most to you at diagnosis, while others at the end of your treatment.**



Talk to your care team about the elements of cancer survivorship that matter to you now.

Here are some common elements to start your conversation and figure out what cancer survivorship means to you:

- **Emotional well-being** and how you are feeling day-to-day
- **Exercise** and how you are eating
- **Family planning** and your role as a parent or grandparent
- **Sexual health**
- Continuing or returning to **work**
- Re-discovering **relationships**
- **Financial planning** and cost of care
- **Spiritual well-being**
- Enhancing your relationship with your **primary care physician (PCP)**



What mattered to me most changed throughout my experience with cancer and with immunotherapy.

I always talked to my care team about the elements of survivorship that were important to me.

What is a survivorship care plan?

A survivorship care plan is a tool to help your oncologist, primary care physician, and other members of your care team to work with you in delivering the best care for your medical, physical, emotional, mental, social, and spiritual needs, even after your treatment ends.

Why do I need a survivorship care plan?

It is important for your entire care team because **it helps all care team members communicate with you and each other about your care in a holistic way.** It is also important as a document that **your caregiver and family can use to know your whole care journey**, especially if you are not able to explain it yourself.

A survivorship care plan for immunotherapy treatment may include:

- **All elements of cancer survivorship** that matter most to you, including emotional well-being, insurance, managing relationships, sexual health, and more
- **Contact information** for your entire care team, including your caregivers
- **Details of your immunotherapy treatment** and any other cancer treatment that you received or are receiving
- How your **side effects have been managed**, including what worked and didn't work
- What your **follow-up** may be after treatment

Emotional well-being

The following pages will answer these questions:

- Is it normal to feel the way I do?
- What can I do to cope?
- What can I do to keep track of my feelings?
- Who can I talk to for more support?
- How can I maintain my general well-being?

Is it normal to feel the way I do?

Living with cancer can be an emotional time. **The feelings you are having are normal responses to this life-changing experience.**

Sometimes, you can cope with these feelings on your own, but other times, you may want help from others. Remember that you are human too, and not just a patient. **You are not alone in your fight against cancer.**

What can I do to cope?

Your emotional, mental, physical, and spiritual well-being are all equally important. Identifying how you are feeling is the first step in taking care of yourself.



Consider taking some time every week to reflect on:

- How you are maintaining **relationships** with others
- The **emotions** that you are feeling (good or bad)

What can I do to keep track of my feelings?

From time to time, use the self-reflection list below to help you tune in to how you are doing. Feel free to make copies of this page.

In the past 7 days:

I felt worried...

Never Rarely Sometimes Often Always

I felt afraid...

Never Rarely Sometimes Often Always

I felt angry...

Never Rarely Sometimes Often Always

I felt helpless...

Never Rarely Sometimes Often Always

I felt guilty...

Never Rarely Sometimes Often Always

I felt anxious...

Never Rarely Sometimes Often Always

I felt in denial...

Never Rarely Sometimes Often Always

I felt _____

Never Rarely Sometimes Often Always

I felt sad...

Never Rarely Sometimes Often Always

I felt hopeful...

Never Rarely Sometimes Often Always

I felt optimistic...

Never Rarely Sometimes Often Always

I felt energetic...

Never Rarely Sometimes Often Always

I felt happy...

Never Rarely Sometimes Often Always

I felt empowered...

Never Rarely Sometimes Often Always

I felt grateful...

Never Rarely Sometimes Often Always

I felt _____

Never Rarely Sometimes Often Always

Consider sharing the self-reflections above with your care team to start a conversation. Discussing your feelings and concerns can help others understand how they can help you.

Who can I talk to for more support?

You may find it helpful to allow others to take part in your journey and learn from their experiences and insights. **It is very common for patients to be active in their community, seek support, and ask for help from other people like:**

- Their **care team**
- Fellow immunotherapy **patients**
- **Support groups** (in your area or online)
- Professionals like **therapists, counselors, or spiritual leaders**
- **Friends and family** members



We know that this is a difficult time for you. Feel free to approach us for additional help. We may be able to introduce you to other resources in your area or online.

How can I maintain my general well-being?

Consider doing the activities listed below to maintain your general well-being. Always check with your care team before starting any new activity.

- Going for a **walk** and getting fresh air
- **Exercising**
- Eating **healthy meals**
- Doing an **activity that you enjoy**
- **Resting**

Talking to your care team and learning more

The following pages will answer these questions:

- How do I talk to my care team?
- What kind of questions can I ask my care team?
- What are some words that I can look up to learn more?
- Which online resources can give me more information about cancer, immunotherapy, and available support?

How do I talk to my care team?

You may feel intimidated about talking to your care team and asking questions. Sometimes, it is also hard to understand what the doctor says, or remember what you wanted to ask and talk about.

But, **asking questions is an important way to address the things that may be worrying you.**

Here are a few tips about asking questions:

- Think about and write down what you want to ask **before** you talk to your care team
- Take notes or ask if you can **record the visit**
- Ask if a **video or transcript** of your telemedicine call may be available
- Ask a **caregiver, family member, or friend to be a second set of eyes and ears** during your conversation with your care team
- If you don't understand your care team's answer to your question, ask for clarification. **Don't be shy about asking for more information!**

For me personally, it was important to stand up and be my own advocate, and to ask **all** of my questions.



I was delighted to learn that I could email my questions to the care team **between my visits**. I wasn't worried about remembering everything during the visit.



Ask your care team how to communicate with them if you have additional questions after your visit.

What kind of questions can I ask my care team?

You can ask **any questions** you would like. To help you get started, here is a list of example questions to think about.

QUESTIONS ABOUT IMMUNOTHERAPY

NOTES

Is immunotherapy right for me?

Are there approved immunotherapies for my cancer?

Is there another patient that I can talk to about their immunotherapy experience?

Will I or my female partner be allowed to get pregnant while I am on immunotherapy?

What are my other options?

If there is no approved immunotherapy for my cancer, then is there an immunotherapy-related or other clinical trial available for me?

QUESTIONS ABOUT BIOMARKERS

NOTES

What are biomarker tests?

What can biomarker tests tell us about my cancer?

QUESTIONS ABOUT HOW IMMUNOTHERAPY MAY BE USED WITH OTHER TREATMENTS

NOTES

Will this immunotherapy be my only treatment? If not, what other treatments could be part of my treatment plan?

Will I have more side effects if I receive more than one type of treatment?

Will I be receiving the treatments at the same time or one after the other?

Will I have to come in multiple times to the hospital or clinic to get multiple treatments, or do they happen all in one day?

Will all of my treatments be in the same hospital or clinic?

How many different treatments can I have?

Can I talk to anyone who has had multiple treatments?

What kind of research has been done about this?

QUESTIONS ABOUT COSTS

NOTES

How much will immunotherapy cost?

Who can I talk to if I have questions about costs, insurance coverage, and payments?

QUESTIONS ABOUT IMMUNOTHERAPY TREATMENT VISITS

NOTES

How often do I need to come to the hospital or clinic for my immunotherapy treatment visits?

How long does each visit usually take?

What happens during each visit?

How will I receive immunotherapy (e.g., an IV, a pill)?

Should someone come with me to each visit?

How will I feel after each visit?

Who can I contact after hours?

If I move, can I continue immunotherapy at another hospital or clinic?

QUESTIONS ABOUT SIDE EFFECTS

NOTES

What kind of side effects might I feel?

When do side effects usually happen?

Who should I talk to if I have side effects?

How will I know when I should call the doctor and when I should just keep track of my side effects?

If I have to see an ER doctor or any other healthcare professional, what do I tell them about my immunotherapy and side effects?

QUESTIONS ABOUT TELEMEDICINE

NOTES

I don't have a computer; can I still have a telemedicine visit?

How long are the telemedicine visits?

How will my doctor do a physical exam if I need one?

Is there another in-person visit after the telemedicine visit?

What are some words that I can look up to learn more?

Below is a list of words and phrases from this guide and their definitions. You can use this list as search terms to learn more about these topics online, to talk to your support groups, or ask your care team about them.

Adjuvant therapy is a type of combination treatment of immunotherapy plus surgery. Surgery may be the first treatment, followed by immunotherapy to help your immune system attack leftover cancer cells that may have been missed during surgery.

Cancer survivorship is the process of living with, through, and beyond cancer, from diagnosis, treatment, and into follow-up.

Immuno-oncology (sometimes called cancer immunotherapy, or just immunotherapy) is using drugs that may help your body's own immune system fight cancer.

Immune system is your body's way of protecting healthy cells from infections and diseases. Your immune system can help prevent unhealthy cells from growing out of control.

Neoadjuvant therapy is a type of combination treatment of immunotherapy plus surgery. Immunotherapy may be the first treatment to help your immune system attack cancer and make the tumor smaller. Surgery will follow.

Perioperative therapy is a type of combination treatment of immunotherapy plus surgery. In this treatment you may have surgery around two immunotherapy treatments. You may start with immunotherapy, then have surgery, and then have immunotherapy again.

Scanxiety is a feeling of anxiety or distress that you may feel before, during, or after you have to do a scan to monitor your cancer during treatment or follow-up.

Survivorship care plan is a tool to help your oncologist, primary care physician, and other members of your care team to work with you in delivering the best care for your medical, physical, emotional, mental, social, and spiritual needs, even after your treatment ends.

MY WORDS AND PHRASES

MY DEFINITIONS



You can always ask your care team
to explain any words that are unclear.

Which online resources can give me more information about cancer, immunotherapy, and available support?

BMS: Exploring the Power of Immuno-Oncology

immunooncology.com

American Cancer Society

cancer.org

Bright Spot Network

brightspotnetwork.org

Cancer and Careers

cancerandcareers.org

Cancer Support Community

cancersupportcommunity.org

Cancer Research Institute

cancerresearch.org

CancerCare

cancercares.org

Caring Bridge

caringbridge.org

ClinicalTrials.gov

ClinicalTrials.gov

Family Reach

familyreach.org

Food and Drug Administration's database

Drugs@FDA or accessdata.fda.gov/scripts/cder/daf

INSPIRE

inspire.com

Stand Up To Cancer

standuptocancer.org

This list of resources is provided as a convenience. Bristol Myers Squibb does not endorse, and is not responsible, for information provided by third-party organization.

What can I do next?

- **Consider visiting the links listed on the previous page** to get more information about cancer, immunotherapy, and support.
- **Consider preparing for any conversations with your care team** by reviewing the example questions in this guide, and writing down any other questions that you might have.
- **Consider the factors in your own life** that may be affected by receiving immunotherapy, and start planning ways to gain more control of your life and treatment.

