

A caregiver's guide to Immuno- Oncology



Things you may want to know as you
care for someone receiving **cancer
immunotherapy**

Immuno-oncology (I-O), sometimes known as **cancer immunotherapy**, or just **immunotherapy**, works differently from other cancer treatments.

Immunotherapy uses drugs that may help the body’s own immune system fight cancer.

Caring for someone with cancer can be a stressful and emotional time.

This guide can help you:

- **Understand** what you can do for **yourself** and your **loved one** (the person you are caring for) to help improve the immunotherapy experience
- **Balance** your emotional well-being with your role as a caregiver
- **Be empowered** to play an active role in your loved one’s treatment

This guide has space for you to **take notes and write down questions**.

Keep this guide for your reference and consider bringing it to your loved one’s appointments.

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Figuring out your role as a caregiver

What does it mean to be a “caregiver”?

Being a caregiver can mean many things, like taking care of a family member, friend, or neighbor. It is an important role that may be challenging at times. Everyone’s experience is different.

It can be difficult to adjust to a set of new responsibilities and a new relationship with your loved one.

Being a caregiver may include helping your loved one:

- Make **treatment decisions** and **monitor side effects**
- Attend their **hospital or clinic visits**
- Prepare for any **phone or video appointments** and use technology to **connect with the healthcare team**
- Manage their **daily routines** (like eating meals, doing chores, helping with child care, taking medications, and running errands)
- Cope with their **health and feelings**
- Figure out how to **pay for treatment**

How do I figure out what my specific role is?

You can **talk to your loved one** about all of their needs and expectations as well as your own.

This is important for a number of reasons:

- To understand the **kind of help that your loved one may need**
- To see what you **can and cannot realistically** do for your loved one
- To discuss **other options** for the times when you are unable to help out

I’m a caregiver for my mother. We’ve always been big on communication, so from the start we talked. She told me about the kind of help she needed, and also the kind of help she **didn’t** need.



What factors should I consider as I become a caregiver?

You may want to think about the following factors:

- How will being a caregiver affect my **relationships with people other than my loved one**?
- How may my **living arrangements** need to change?
- Who can **help or share responsibilities with me**?
- Will I need to take **time off work**?
- Will I need **long-term financial support**?
- Where will I find support to **help take care of myself**?

Caring for my sister, I have to wear many hats. I help with groceries, take her to appointments, and help her stay positive.



Learning more about cancer and immunotherapy

Who is on my loved one's healthcare and care team?

Your loved one's **healthcare team** consists of **doctors, nurses, and other healthcare professionals** who work together to help with their care.

Your loved one's **care team** includes their **healthcare team**, as well as their **friends, family, and caregivers**.

Your loved one's care team is dedicated to **helping you and your loved one through their journey**. You can lean on them for support with any part of your loved one's experience with immuno-oncology.

The care team may include:

- **Oncologists, primary care physicians (PCPs), surgeons, and any other specialists** that your loved one sees
- **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 might my loved one's journey through immunotherapy be like, and how can I help?

As a **patient**, they might:

BEFORE TREATMENT

Learn about their treatment options.



Talk to the healthcare team about different treatment options, including immunotherapy and combinations of treatments, as well as methods for receiving treatments.



Work with the healthcare team to make the best treatment decision.

DURING TREATMENT

Attend telemedicine visits at home or go to in-person treatment visits at the hospital or clinic.



Keep track of and let the healthcare team know about any side effects.

AFTER TREATMENT

Continue to keep track of any side effects and talk to the healthcare team about things that may become important after the treatment is finished.

As a **caregiver**, you can:

BEFORE TREATMENT

Help your loved one research and learn more about treatment options.



Help your loved one talk to the healthcare team about different treatment options, including immunotherapy and combinations of treatments, as well as methods for receiving treatments.



Help your loved one and their healthcare team make the best treatment decision.

DURING TREATMENT

Help your loved one prepare for telemedicine or in-person treatment visits. This may include transportation to and from the hospital or clinic, and support with technology at home.



Help your loved one identify and discuss side effects together with the healthcare team.

AFTER TREATMENT

Continue to help your loved one keep track of any side effects and help them figure out things that may become important after treatment is finished.

Where can I find more information about immunotherapy?

Your loved one's **healthcare team** is the best source of information.

It may be hard to figure out how to navigate the healthcare world and stay strong for your loved one at the same time. You may find yourself gathering information on a range of topics: **the disease itself, immunotherapy as a treatment option, methods for receiving treatments, possible side effects, health insurance, and more.**

First, ask your loved one if you can talk to the healthcare team on their behalf. If your loved one gives you permission, then you may consider asking:

- Your **questions about immunotherapy**
- About telemedicine services for **remote visits**
- For recommendations of **trustworthy educational resources**
- About any **support that may be available** locally or online

At the start of my husband's treatment, I got a little overwhelmed trying to do research by myself. I talked to the doctor, who gave me resources and recommended peer groups for caregivers like me. I thought that was very helpful.



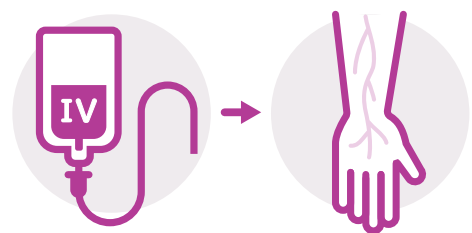
Understanding methods for receiving immunotherapy, treatment visits, and possible side effects

How might my loved one receive immunotherapy?

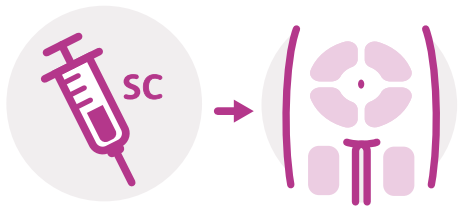
If your loved one and the healthcare team decide to start immunotherapy, you might wonder how it will be given. There are **different ways** to receive immunotherapy, such as through a vein (intravenous or IV) or under the skin (subcutaneous or SC).

SC injections are different than other injections your loved one might be familiar with, like routine vaccinations. SC injections for immunotherapy can take several minutes to administer the medicine. The method your loved one will use may depend on their treatment plan, the place where they receive care, and their personal preferences.

The **intravenous (IV) method** is a common way to deliver treatment directly into the vein. This method has been used for a long time as a way to give cancer treatment. Receiving treatment through the IV method can potentially take 30 minutes or more.



The **subcutaneous (SC) method** allows treatment to be given under the skin, usually in the stomach area (abdomen) or in the thigh area. The injection administration time typically is about 2 to 8 minutes. The SC injection is made up of the cancer treatment and hyaluronidase. Hyaluronidase helps the cancer treatment get absorbed into the body when injected under the skin. Some patients prefer this method because they might feel more comfortable when receiving treatment, spend less time at the clinic or hospital, and have more flexibility in scheduling appointments.



While SC and IV methods may have different treatment doses, both methods work to treat cancer. Researchers perform careful studies to make sure the SC method works just as well as the IV method in treating cancer. **The best choice for your loved one depends on their treatment plan and personal comfort.**

It's been helpful to talk with the healthcare team about the methods that might work best for my loved one to receive their treatment.



Here are some questions you can discuss with your loved one and the healthcare team to help decide which method might be right for them:

- What are the **main differences** between the methods for receiving immunotherapy?
- What might be the **possible side effects** for each method of receiving immunotherapy?
- How much **time does your loved one prefer to spend at the clinic or hospital** for their treatment?
- Does your loved one need **flexibility in scheduling appointments**?
- Which method does your loved one **feel more comfortable** with?
- Will your loved one receive **other treatments that might require an IV**?
- Who can I talk to if I have questions about **the costs and insurance coverage** for each method of receiving immunotherapy?

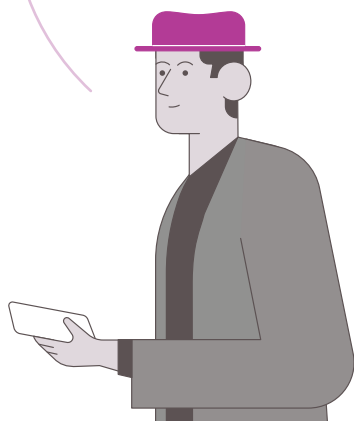
How can I help my loved one prepare for treatment visits?

As a caregiver, you may be going to treatment visits with your loved one.

Consider doing the following before a treatment visit:

- Call ahead to **confirm the visit** and **ask what your loved one might need to bring or do to prepare**
- **Arrange transportation** to and from the visit
- **Write down any questions** that you might have and topics you may want to discuss with the healthcare team
- **Keep your loved one's health information** in one place and bring it to every visit
- Remind your loved one to **wear comfortable, loose clothing** to make it easier for them to receive their treatment
- **Bring something to do while waiting** (both for yourself and your loved one)

I'm always there with my mom during her treatment visits.



What is telemedicine?

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

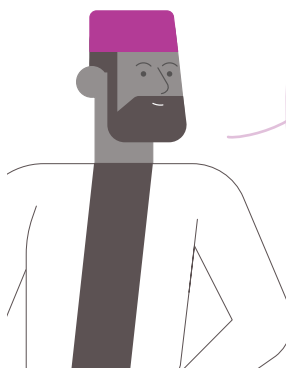
How can I help my loved one prepare for telemedicine visits?

It's important to have a good home set-up in preparation for the telemedicine visit.

Consider doing the things listed below, in addition to what you would do to prepare for a treatment visit, a few days before your telemedicine visit:

- Asking your healthcare team about **what devices or technology your loved one may need**
- Asking the healthcare team to arrange for a **translator to join the call if needed**
- Inviting **another caregiver, family member or friend to join the call** even if they are far away
- **Positioning the camera to show side effects** that your loved one may not be able to do themselves

I live far away from my daughter, but I am still able to attend her telemedicine visits and support her.



What are some possible side effects of immunotherapy?

Your healthcare team will have a better idea of what side effects you may experience.

Ask your healthcare team for a list of side effects so you and your loved one can recognize them as soon as they occur.



The healthcare team can give you a list of possible side effects for your loved one's specific immunotherapy and administration method. Talk to the healthcare team about the kind of resources you can use to understand possible side effects of immunotherapy.

The side effects that your loved one may have will depend on the treatment or combination of treatments they are receiving, how they are receiving the treatments, and how their immune system reacts to the treatments.

Everyone's immunotherapy experience will be different.

Remember, side effects can happen at any time during or after immunotherapy. **Since the immune system takes care of the whole body, these side effects may happen anywhere in the body, and some may be serious, life-threatening, and life-long.**

You can find more information about the possible effects of immunotherapy in "A patient's guide to Immuno-Oncology."

What should I do if my loved one has side effects?

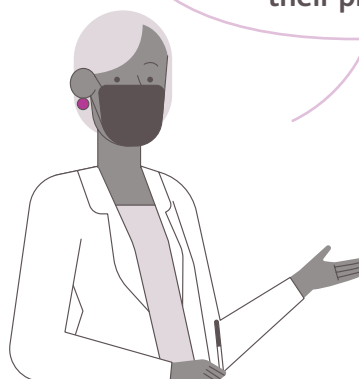
It is important to keep close track of side effects and keep the healthcare team up-to-date on how your loved one is feeling.

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

- Keep a journal to track how your loved one feels every day
- Note how your loved one feels right after their treatment visits
- Let the healthcare team know if your loved one has changes that are new, different, or bothersome
- **Tell the healthcare team about side effects as soon as possible! This may help them manage the side effects earlier**

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

Tracking the patient's side effects is key to monitoring their progress.



Taking care of yourself

Is it normal to feel the way I do?

Caring for someone with cancer can be a stressful and emotional time. **It is normal to react with shock, sadness, fear, guilt, anger, or even numbness.** As you take on the role of a caregiver, you may feel physical, emotional, and spiritual challenges.

Sometimes you can cope with these feelings on your own, but other times you may want help from others. **You are not alone.**

At the start of my partner's treatment, I was a full-time caregiver and a dad. But it was important for me to realize that **it's okay to ask for help!**



How can I maintain my general well-being?

It may be hard for you to find time to take care of your own well-being. **But to take care of your loved one, you have to take care of yourself too.**

Your emotional, physical, and spiritual well-being are all equally important.

Consider doing the activities listed below to maintain your general well-being:

- Going for a walk and getting fresh air
- Exercising
- Doing an activity that you enjoy
- Resting
- Eating healthy meals
- Spending quality time with friends and family without your loved one

Some caregivers find it helpful to make a “self-care plan” in advance.

Here is an example of what a self-care plan may look like:

My self-care plan

1. Meditate for 10 minutes every morning
2. Go to a peer-to-peer meeting on Tuesdays
3. Reflect on my emotions every week
4. Play my cello at least twice a week

How do I cope with changing relationships?

While it can be fulfilling to support your loved one, it is no easy task. You may struggle with how your relationship with your loved one changes through their cancer experience. Both of you are going through a difficult time and may react in different ways. **Your relationship may go through ups and downs.**

Your emotions may change from diagnosis, treatment, and the months and years that follow. **You may find different ways to help yourself cope at each stage.** It's important to find what works for you.

Consider taking some time every week to reflect on:

- How you are **adapting to your relationship with your loved one**
- How you are **maintaining your relationships with your friends and family**
- The **emotions that you are feeling** (good and bad)
- How you are **feeling physically and your energy levels**



Self-reflections

Identifying how you are feeling is the first step to taking care of yourself.

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 sad...

Never.....Rarely.....Sometimes.....Often.....Always

I felt tired...

Never.....Rarely.....Sometimes.....Often.....Always

I felt exhausted...

Never.....Rarely.....Sometimes.....Often.....Always

I felt _____

Never.....Rarely.....Sometimes.....Often.....Always

In the past 7 days:

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

You may find it helpful to allow others to take part in your journey and learn from their experiences and insights. **Consider sharing the self-reflections above** to start a conversation. Discussing your feelings and concerns can help people understand how they can help you.

At first, I didn't want to ask for help. But after I talked to the care team, they connected me with a therapist, and it helped me find ways to cope.



Who can I talk to for more support?

Don't try to do it all on your own. Ask for help if you need it, both physically and emotionally. Some caregivers like to be active in their community, seek support, and ask for help from other people like:

- Fellow caregivers
- Support groups (in your area or online)
- Professionals like therapists, counselors, or spiritual leaders
- Friends and family members

I talked to the social workers on my husband's care team, and they helped me come up with a plan to keep connected with friends.





I continue to talk to other caregivers online. I like sharing my story and offering support to other caregivers who need it.

I was nervous about going back to work after taking time away to care for my mom.

I wasn't sure how to address the gap in my resume, but the care team connected me with someone who could help.



How do I talk to the healthcare team?

Sometimes it is 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 couple of tips about asking questions:

- Think about and write down what you want to ask **before** you talk to the healthcare team
- Take notes or ask if you can record the visit
- If you don't understand the healthcare team's answer to your question, ask for clarification. **Don't be shy about asking for more information!**

What kind of questions
can I ask the healthcare team?

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

QUESTIONS ABOUT RECEIVING
IMMUNOTHERAPY

How will my loved one receive immunotherapy
(e.g., the intravenous method, the subcutaneous
method, or a pill)?

Do some methods of receiving immunotherapy
work better than others?

Have other people like my loved one received
immunotherapy?

How will we know if the immunotherapy
is working?

What happens if my loved one’s cancer gets worse
while on immunotherapy?

What should my loved ones do if they don’t
want to receive immunotherapy anymore?

What should we tell other doctors (e.g.,
primary care physician, ER doctor) about the
immunotherapy that my loved one is receiving?

QUESTIONS ABOUT COSTS

How much will immunotherapy cost?

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

QUESTIONS ABOUT TREATMENT VISITS

How often are the treatment visits, and how long
does each visit usually take?

Is there support available if my loved one can’t get
to the hospital or clinic?

What happens during each treatment visit?

How do we prepare for each treatment visit (e.g.,
does my loved one need to fast)?

Can I stay with my loved one during their visit?

What happens if my loved one misses one
of their visits?

QUESTIONS ABOUT SIDE EFFECTS

What kind of side effects might my loved one have with each method of receiving immunotherapy?

Who should we talk to if my loved one has side effects?

How will we know when to call the doctor and when to just keep track of the side effects?

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

Will immunotherapy affect my loved one's ability to have children?

QUESTIONS ABOUT TELEMEDICINE

How long are the telemedicine visits?

How will the doctor do a physical exam if my loved one needs one?

My loved one doesn't have a computer; can they still have a telemedicine visit?

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

American Cancer Society
[cancer.org](https://www.cancer.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](https://www.accessdata.fda.gov/scripts/cder/daf) or
www.accessdata.fda.gov/scripts/cder/daf

Help for Cancer Caregivers
helpforcancercaregivers.org

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 organizations.

What can I do next?

Here is a checklist that you might want to look at from time to time to figure out what to do next. Please feel free to update this checklist to fit your needs.

- ☐ Talk to my loved one about their needs and my availability, in order to understand what they need and set realistic expectations.
- ☐ Track my loved one's side effects, and tell the healthcare team about them.
- ☐ Regularly reflect on my physical, emotional, and spiritual well-being, and update my self-care plan as my role as a caregiver changes.



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