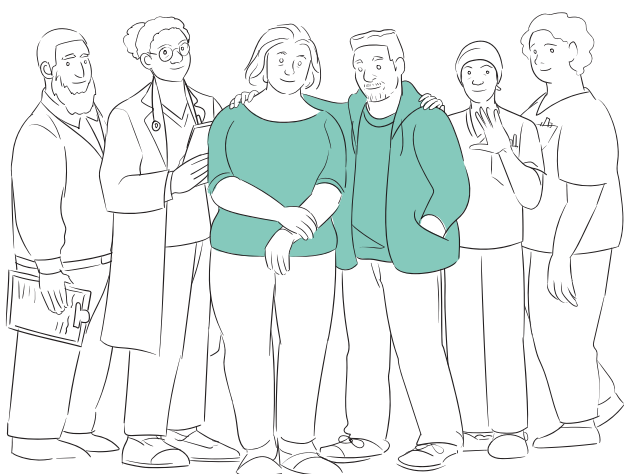


# A caregiver's guide to **Immuno- Oncology**



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

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**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.

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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 **care partner** (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 care partner'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 care partner'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 care partner.

Being a caregiver may include helping your care partner:

- 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 care 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 care partner** 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 care partner may need**
- To see what you **can and cannot realistically** do for your care partner
- 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.

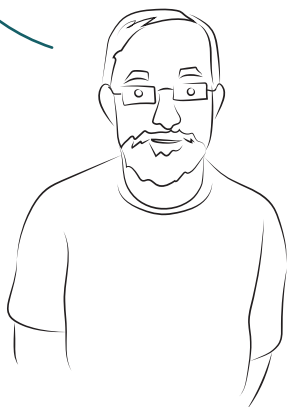


## What factors should I consider as I become a caregiver?

You may want to think about the following factors:

- How will being a caregiver affect my **relationships with people other than my care partner?**
- How will 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

### What is a care team?

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

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

The care team may include:

- **Oncologists, primary care physicians (PCPs), surgeons,** and any other **specialists** that your care partner 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**



**Ask your care partner's oncologist** who is on the care team.

## What might my care partner'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 care team about different treatment options, including immunotherapy, and combinations of treatments.



Work with the care 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 care team know about any side effects.

### AFTER TREATMENT

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

As a **caregiver**, you can:

### BEFORE TREATMENT

Help your care partner research and learn more about treatment options.



Help your care partner talk to the care team about different treatment options, including immunotherapy, and combinations of treatments.



Help your care partner and their care team make the best treatment decision.

### DURING TREATMENT

Help your care partner 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 care partner identify and discuss side effects together with the care team.

### AFTER TREATMENT

Continue to help your care partner 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 care partner's **care 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 care partner at the same time. You may find yourself gathering information on a range of topics: **the disease itself, immunotherapy as a treatment option, side effects, health insurance, and more.**

**First, ask your care partner if you can talk to the care team on their behalf.** If your care partner 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 treatment visits and possible side effects

### How can I help my care partner prepare for treatment visits?

As a caregiver, you may be going to treatment visits with your care partner.

Consider doing the following before a treatment visit:

- Call ahead to **confirm the visit** and **ask what your care partner 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 care team
- **Keep your care partner's health information** in one place and bring it to every visit
- **Bring something to do while waiting** (both for yourself and your care partner)

My mom and I always watch movies together during her infusion 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 care team through texts, direct messages, or online health records.

## How can I help my care partner 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 care team about **what devices or technology your care partner may need**
- Asking the care 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 care partner 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 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 you and your care partner can recognize them as soon as they occur.**



**The care team can give you a list of possible side effects for your care partner's specific immunotherapy.** Talk to the care team about the kind of resources you can use to understand possible side effects of immunotherapy.

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

## Taking care of yourself

### What should I do if my care partner has side effects?

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

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

- Keep a journal to track how your care partner feels every day
- Note how your care partner feels right after their treatment visits
- Let the care team know if your care partner has changes that are new, different, or bothersome
- **Tell the care 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 care 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.**



### 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 care partner, 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 care partner

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

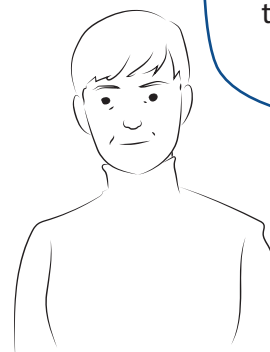
## How do I cope with changing relationships?

While it can be fulfilling to support your care partner, 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 care partner**
- 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**



It’s nice to take some time for yourself. I find that journaling and meditation help a lot. Just ten minutes of meditation every morning does wonders.

## 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

#### 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:

- Your care partner's care team
- 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 care 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 care team
- Take notes or ask if you can record the visit
- If you don't understand the care 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 care 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 IMMUNOTHERAPY

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Have other people like my care partner received immunotherapy?

.....

How will we know if the immunotherapy is working?

.....

What happens if my care partner's cancer gets worse while on immunotherapy?

.....

What should my care partner 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 care partner is receiving?

.....

## QUESTIONS ABOUT COSTS

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How much will immunotherapy cost?

.....

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

.....

## QUESTIONS ABOUT TREATMENT VISITS

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

.....

Is there support available if my care partner 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 care partner need to fast)?

.....

Can I stay with my care partner during their visit?

.....

What happens if my care partner misses one of their visits?

.....

## QUESTIONS ABOUT SIDE EFFECTS

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What kind of side effects might my care partner have?

.....

Who should we talk to if my care partner 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 care partner's immunotherapy and side effects?

.....

## QUESTIONS ABOUT TELEMEDICINE

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How long are the telemedicine visits?

.....

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

.....

My care partner doesn't have a computer; can they still have a telemedicine visit?

.....

## Next steps

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

BMS: Exploring the Power of Immuno-Oncology  
[immunooncology.com](https://immunooncology.com)

American Cancer Society  
[cancer.org](https://cancer.org)

Cancer Support Community  
[cancersupportcommunity.org](https://cancersupportcommunity.org)

Cancer Research Institute  
[cancerresearch.org](https://cancerresearch.org)

CancerCare  
[cancercare.org](https://cancercare.org)

Caring Bridge  
[caringbridge.org](https://caringbridge.org)

ClinicalTrials.gov  
[ClinicalTrials.gov](https://ClinicalTrials.gov)

Family Reach  
[familyreach.org](https://familyreach.org)

Food and Drug Administration's database  
[Drugs@FDA](mailto:Drugs@FDA) or  
[www.accessdata.fda.gov/scripts/cder/daf](https://www.accessdata.fda.gov/scripts/cder/daf)

Help for Cancer Caregivers  
[helpforcancercaregivers.org](https://helpforcancercaregivers.org)

INSPIRE  
[inspire.com](https://inspire.com)

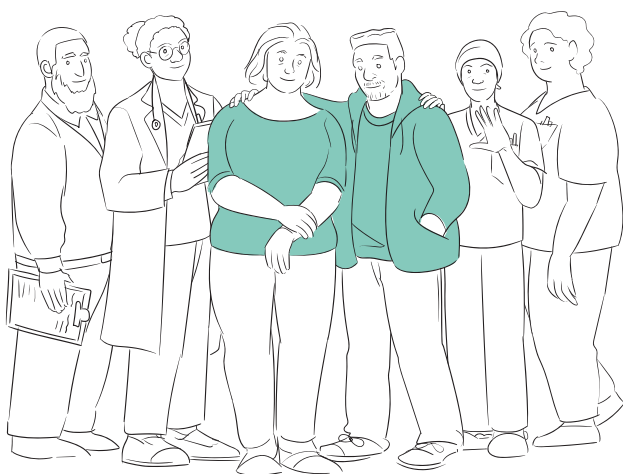
Stand Up To Cancer  
[standuptocancer.org](https://standuptocancer.org)

*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 care partner about their needs and my availability, in order to understand what they need and set realistic expectations.
- Track my care partner's side effects, and tell the care 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.



[www.immunooncology.com](http://www.immunooncology.com)



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