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Introduction

Caring for someone with cancer can be a stressful and emotional time. **Immunology (I-O)**, sometimes known as **cancer immunotherapy**, or just **immunotherapy**, works differently from other cancer treatments. Your role as a caregiver may be different too.

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

This guide can help you:

- **Understand** what you can do for your care partner (the person you are caring for) and yourself to help improve the immunotherapy experience
- **Empower** you 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.

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 ever-changing role, unique to each person and patient.

As a caregiver, you are coming into this role with your existing life in tow. It can be difficult to adjust to a set of new responsibilities.

Being a caregiver may include:

- Helping your care partner **make treatment decisions**
- Going with your care partner to their **hospital or clinic visits**
- Helping your care partner with **daily routines** (like eating meals, doing chores, managing medications, and running errands)
- Helping your care partner **cope with their health and feelings**
- Helping your care partner figure out how to **pay for treatment**

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



Figuring out your role as a caregiver

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 needs**
- To see what you **can and cannot realistically** do for your care partner
- To make sure that you are **meeting the needs of 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 think about as I consider becoming a caregiver?

You may want to think about the following factors:

- Will being a caregiver affect my relationships with people other than my care partner?
- Will my living arrangements need to change?
- Who can take over or share responsibilities with me?
- Will I need to take time off work?
- Will I need long-term financial support?

Helping your care partner learn more about their cancer and immunotherapy

What might my care partner's journey through immunotherapy be like, and how can I help?

**As a patient,
they might:**

Learn about their treatment options.



Talk to the cancer care team about different types of treatment, including immunotherapy, as options. Your cancer care team includes your doctor, nurse, and others.



Make the decision of whether or not to receive immunotherapy.



Go to the hospital or clinic for treatment visits.



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

**As a caregiver,
you can:**

Help your care partner learn more about treatment options.

Help your care partner talk to the cancer care team about different types of treatment, including immunotherapy, as options.

Help your care partner make the decision of whether or not to receive immunotherapy.

Help your care partner prepare for treatment visits, which may include transportation to and from the hospital or clinic.

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

Helping your care partner learn more about their cancer and immunotherapy

Where can I find more information about immunotherapy?

Your care partner's **cancer 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 cancer care team on their behalf. If your care partner gives you permission, then you may consider asking about:

- Your **questions about immunotherapy**
- Recommendations of **trustworthy resources**
- Any **support that may be available** at your hospital or clinic

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.



Helping your care partner learn more about their cancer and immunotherapy

How do I talk to the cancer care team?

You may feel intimidated about talking to your cancer 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 couple of tips about asking questions:

- Think about and write down what you want to ask **before** you talk to the cancer care team.
- Take notes or ask if you can record the visit.
- If you don't understand the cancer 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 cancer 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

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 he or she doesn't want to receive immunotherapy anymore?

What should we tell other doctors (e.g., family doctor, ER doctor) about the immunotherapy that my care partner is receiving?

Helping your care partner learn more about their cancer and immunotherapy

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 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

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?

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. Before a treatment visit:

- Call ahead to **confirm the visit** and **ask what your care partner might need to bring, or what they might 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 the cancer care team (like new side effects).
- **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.



Understanding treatment visits and possible side effects

What are some possible side effects of immunotherapy?

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

Ask your cancer care team for a list of side effects so you and your care partner can recognize them as soon as they come up.

The side effects that your care partner may get will depend on the immunotherapy they are receiving, and how their immune system reacts to it. Everyone's immunotherapy experience will be unique.

Side effects may happen during or after immunotherapy treatment. Since the immune system takes care of the whole body, side effects can also happen in many organs. Some side effects may be serious.

The cancer care team can give you a list of possible side effects for your care partner's **specific immunotherapy**.

A list of side effects for **any** approved drug can be found on the Food and Drug Administration's database (Drugs@FDA), and sometimes on the drug's website.



Understanding treatment visits and possible side effects

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

Tell the cancer care team about any changes that are **new, different, or bothersome**. It is important to keep close track of side effects and keep the cancer care team up-to-date on how your care partner feels.

Patients know their bodies best, and can tell when they are feeling good or bad. It may help to keep a record of side effects as they come up, so that you can share them with us — the cancer care team.



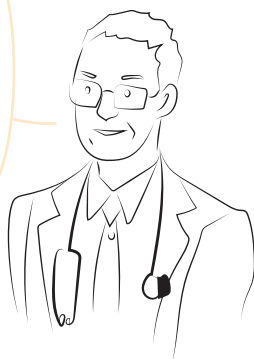
Here are some tips on how you can identify, keep track of, and report your care partner's side effects:

- 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 cancer care team know if your care partner has changes that are new, different, or bothersome.
- **Tell the cancer care team about side effects as soon as possible! This may help them manage the side effects earlier.**

For fear of being a nuisance, some patients and caregivers are reluctant to report side effects to the cancer care team.

Do not hesitate!

We are here to help you, 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?

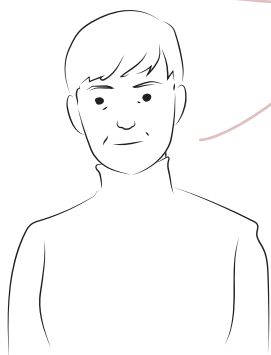
Caring for someone with cancer can be a stressful and emotional time. It is normal to react with shock, sadness, fear, or even anger. As you take on the role of a caregiver, you may feel physical, emotional, and spiritual challenges.

Sometimes you can cope with these feelings on your own, but sometimes you may want help from others. Remember that you're human too and not just a caregiver. **You are not alone.**

What can I do to cope?

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

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.



Consider taking some time every week to reflect on:

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

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

Taking care of yourself

Self-reflections

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

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.

Taking care of yourself

Who can I talk to for more support?

Some caregivers like to be active in their community, seek support, and ask for help from other people like:

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

We know that this might be a hard time for you. Come talk to us — your cancer care team — for any help. We may be able to introduce you to other resources in your area.



How can I maintain my general well-being?

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

Taking care of yourself

Are there any other ways to cope?

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

Next steps

Which online resources can give me more information about immunotherapy?

You can stay up-to-date on immunotherapy research by visiting the following websites:

BMS: Exploring the Power of Immuno-Oncology
www.immunooncology.com

Cancer Research Institute
www.cancerresearch.org

American Cancer Society
www.cancer.org

Stand Up to Cancer
www.standup2cancer.org

Cancer Support Community
www.cancersupportcommunity.org

ClinicalTrials.gov
www.ClinicalTrials.gov

CancerCare
www.cancercare.org

Food and Drug Administration's database
Drugs@FDA or
<https://www.accessdata.fda.gov/scripts/cder/daf/>

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.
- With my care partner's permission, ask the cancer care team questions about anything that was unclear to me (like the disease itself, immunotherapy as a treatment option, side effects, etc.).
- Track and continue to track my care partner's side effects, and tell the cancer 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
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