A caregiver’s guide to Immuno-Oncology in Blood Cancers

This guide will help you understand immunotherapy in blood cancers, and what you can do for the patient and yourself to improve the treatment experience.
Introduction

How does immunotherapy work with the immune system to fight cancer?

How is immunotherapy different from other types of cancer treatment?

What side effects can be expected from immunotherapy?

What can I do as a caregiver?

What can I do to cope?

Is it normal to feel this way?

Where can I find more information?

Notes
You may already know about some of the treatment options available for blood cancers, such as chemotherapy, radiation, targeted therapy or stem cell transplant. With advances in science, there’s now another way to treat certain cancers: immuno-oncology.

Immuno-oncology uses drugs known as immunotherapies to help the body’s immune system fight cancer. ‘Immuno’ in immuno-oncology refers to the immune system. The immune system is the body’s natural defense against illness and disease such as cancer.

This guide will help you understand immunotherapy. Keep this for your reference. We’ve provided blank space for you to take notes and write down any questions you may have as you read through the guide.
Immunotherapy uses the body’s own immune system to help fight cancer. Here’s an analogy to explain the concept:

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

Cancer cells are like weeds in the lawn. Sometimes the soil can allow weeds to grow and spread, and soon, the entire lawn suffers as the grass competes for space and nutrients.
Immunotherapies are like adding weed-control fertilizer to the soil. It enriches the lawn’s existing soil.

Now the soil can help keep the weeds under control and can maintain the lawn’s health.

**NOTES**

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How is immunotherapy different from other types of cancer treatment?

Immunotherapy is a unique approach that uses the body’s immune system to help fight cancer. To understand how immunotherapy is different from other treatments, let’s revisit the lawn analogy.

If the body is like a lawn, the patient and the healthcare team will decide on how to remove the weeds (cancer cells) while doing a lesser amount of damage to the grass (good cells).

Chemotherapy is like spraying a general weed killer on the whole lawn. This approach may not kill all the weeds and may also harm some grass.

Radiation is like increasing the power of the sun with a magnifying glass to target and dry the weeds out, but in the process, some of the grass can also be damaged.
With targeted therapy, weeds are directly sprayed with weed killer. Grass may still be damaged.

A stem cell transplant is like putting a patch of healthy new lawn into the existing lawn to help with weed control. However, new grass may not grow in the transplanted section.

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 the lawn. But too much fertilizer in the soil might harm the lawn.

Ask the healthcare team about the different treatment options available to the patient.
The side effects that the patient feels depend on the immunotherapy and how the immune system reacts to that treatment.

Since the immune system takes care of the whole body, side effects can happen in many organs. Some of these side effects may be serious.

**What side effects can be expected from immunotherapy?**

Encourage your loved one to report symptoms if they feel unwell. Help them keep track of how they feel physically, and update the healthcare team if you see any changes.

The healthcare team will have a better idea of what side effects to expect. Ask the healthcare team for a list of side effects so you can recognize them as soon as they come up and help your loved one contact their healthcare provider.

Side effects may happen during or after immunotherapy treatment. Whether side effects occur will depend on the type of therapy and how the immune system responds. Everyone’s experience is unique.
NOTES

Doc, I need to let you know...

What side effects can be expected from immunotherapy?
What can I do as a caregiver?

As a caregiver, there are many ways to support the patient. Make sure the patient is comfortable with how you plan to help them. Check in with them often, as their needs may change over time.

**Talk with the patient**

- Ask them how they’re doing, and keep an eye out for changes or symptoms
- Ask if they’d like help with day-to-day tasks, like chores

**Help with appointments**

- Remind the patient to attend appointments
- Arrange transportation to and from appointments
- Offer to accompany them to appointments
- Call ahead to confirm the appointments, and find out what they need to bring (like a list of medications)
- Take notes or ask to record the conversation (sometimes the amount of information received at each appointment can be overwhelming)
- Ask all the questions that come to mind

**Don’t forget you are human**

- Take the time to do activities you enjoy
- Make time for yourself
- Tune in to how you are feeling
- Ask for help if you feel overwhelmed
Appointment checklist

- Bring a pen and notepad
- Write down any questions you or your loved one has in advance
- Mark the date and time on a calendar
- Make any necessary arrangements for traveling to and from the appointment

Important contact information

Nurse ..............................................
Oncologist .......................................  
Therapist .........................................
Support group ....................................

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What can I do to cope?

Supporting a loved one with cancer can be demanding. Your emotional well-being is extremely important. There are many ways for you to take care of your emotional health, like:

• Talking to the patient
• Talking to the healthcare team
• Talking to friends and family
• Talking to a counselor
• Finding local or online support groups
• Finding time for yourself
• Setting aside quiet time
• Journaling
• Going for a walk
• Getting fresh air
• Meditating
• Exercising
• Resting

It is common for caregivers to seek support from other people. If there are aspects of your role that you are uncomfortable discussing with those closest to you, consider speaking with others in your community, such as:

• The healthcare team
• Fellow caregivers or patients
• Support groups
• Therapists
• A religious advisor
As a caregiver, it is important to remember that you have emotional needs as well. You can share your feelings even if the person in your care does not want to.

Reflect

Take a look at the questions below to see how you can expand your support network:

Do you talk to others about yourself or your situation?
Never  Rarely  Sometimes  Often  Always

Do you have someone to confide in or talk to about yourself or your situation?
Never  Rarely  Sometimes  Often  Always

Do you have someone who will listen to you when you need to talk?
Never  Rarely  Sometimes  Often  Always

The healthcare team knows this is a difficult time for you. Feel free to approach them to request additional help. They may be able to introduce you to other caregiver resources in your area.
Is it normal to feel this way?

Caring for someone diagnosed with cancer is an emotional time. The feelings you are having are a normal part of becoming a caregiver.

Sometimes we can cope with these feelings on our own, but other times we need help from others. Remember that you’re human too and not just a caregiver.

Identifying how you are feeling is the first step to taking care of yourself. Periodically, take a look at the questions on the next page to help you dial into how you are feeling.

Feel free to make copies of this page.

Consider sharing the next page with someone to start a conversation. Discussing your feelings and concerns can help others understand how they can help you.
Reflect

*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 in denial…**
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

Is it normal to feel this way?
You probably still have many questions about immunotherapy. Keep a list of questions and concerns and bring them with you to your friend or family member’s next appointment.

You can also contact your healthcare team or visit the following websites for more information.

American Cancer Society
www.cancer.org

CancerCare
www.cancercare.org

Cancer Research Institute
www.cancerresearch.org

Cancer Support Community
www.cancersupportcommunity.org

ClinicalTrials.gov
www.clinicaltrials.gov

International Myeloma Foundation
www.myeloma.org

Leukemia and Lymphoma Society
www.lls.org

Multiple Myeloma Opportunities for Research and Education
www.mmore.org

Multiple Myeloma Research Foundation
www.themmrf.org

Stand Up to Cancer
www.standup2cancer.org

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