MAKING SENSE OF THE

Transplant Journey

Whether you are preparing for a transplant or recovering from one, you may be feeling frustrated, scared, or angry. On the other hand, you may feel hopeful—some people see their transplant as a new chapter. Either way, you have already been through a lot, and there are probably times when you're simply overwhelmed.

That's a common experience, and it can make it hard to process information. We created this resource because we understand. Read it when you're ready and revisit it when you need a reminder that **you're not alone**.

What to Know About Recovery

You might have heard your doctor talk about the "100-day mark" and "GVHD." Here's what to know:

THE 100-DAY MARK

This phrase refers to the first 100 days after your transplant. That's usually when your healthcare team is keeping the closest eye on your recovery. They are looking out for signs of complications, like GVHD.

WHY THIS MATTERS

After the 100-day mark, you may have fewer check-ins with your team. **This is when it becomes even more important for you and your caregiver to be on the lookout** for anything that seems new and unusual. Find out more on page 3.

GVHD

Graft-versus-host disease (GVHD) is a complication that can occur after a stem cell transplant. It happens when the donor cells (the "graft") attack organs and tissues in the body (the "host").

ACUTE & CHRONIC GVHD

These are the 2 main types. Acute GVHD usually develops within the first 100 days after transplant and often affects the skin, gut, and liver. Chronic GVHD usually develops later and has a broader range of symptoms—but these are not hard and fast rules. That's why **self-monitoring both before and after 100 days is so important.**

MEREDITH A. Cowden FOUNDATION

LEARN MORE ABOUT THE TYPES OF GVHD

GVHDALLIANCE.ORG

DO WHAT YOU CAN,

When you can

STAY CONNECTED

Some people feel lonelier than expected. Texts and emails with loved ones can help. When you feel up to it, video calls can make you feel especially close to those you love.

TAKE A MIND & BODY APPROACH

Recovery is emotional and physical. Rest, proper nutrition, movement, and emotional support all matter.

LEAN ON YOUR SUPPORT SYSTEM

Consider asking someone you trust to come with you to appointments or open up to new people through counseling.

Email **riseambassadors@cowdenfoundation.org** for support.

TALK IT OUT

On your terms

MAINTAIN BOUNDARIES
Share only what you feel comfortable with.

BE SPECIFIC
Being honest about what you need—including when it's simply space.

CHOOSE YOUR CIRCLE
Identify your go-to people early on.

VISIT THE MEREDITH A. COWDEN FOUNDATION

to learn more about its mission of sharing research and information for those working with and impacted by GVHD.

COWDENFOUNDATION.ORG

Listen to your body

HERE ARE SOME THINGS TO LOOK OUT FOR:

Skin, Nails, Hair
Rash, itch, discoloration, lumpy or dimpled appearance, nail changes, hair loss or thinning

Joints and Muscles
Pain, stiffness, cramps, weakness

Eyes
Dry, teary, red, blurry vision, light sensitivity

Mouth
Trouble opening, sores, pain, dryness, difficulty swallowing. Changes in mouth sensitivity that make eating certain foods uncomfortable (e.g., spicy, acidic, salty, or hot foods)

Lungs
Shortness of breath, cough

Stomach and Intestines
Nausea, vomiting, diarrhea, cramping, weight loss

Liver
Yellowing of skin or eyes, dark urine, fatigue

Genitals
Irritation, itching, dryness, burning, pain with sexual activity

This is not a complete list of changes you may notice. **Tell your doctor right away about anything that seems new and unusual**.

Share this list with a caregiver, too. Symptoms are not always easy to recognize or describe, and your caregiver might notice changes before you do.

ANYTHING YOU WANT TO TALK ABOUT?

Use this section to jot down notes or anything you want to discuss with your doctor.