



Living
BEYOND



cGVHD

A COMPREHENSIVE GUIDE
FOR TRANSPLANT PATIENTS:
HIGHLIGHTS ON GRAFT VS.
HOST DISEASE



GVHD: Graft-versus-Host Disease.

Welcome Message

Welcome to our chronic graft vs. host disease (cGVHD) patient guide. This booklet is designed to provide you with essential information and support, whether you are newly diagnosed or have been managing cGVHD for some time. We hope it will be a valuable resource for you and your loved ones. Living with cGVHD can be challenging, but you are not alone.

The information in this booklet can serve as a helpful tool throughout the course of your post-transplant journey and management. However, it is not intended to replace the information provided by your physician and transplant team, nor is it a substitute for the discussions you should have with your transplant team. Always consult your physician and transplant team if you have any questions or concerns regarding your treatment.

In this booklet, you will find:

- 03 Insights Into Bone Marrow Transplants and Understanding cGVHD
- 05 Living With cGVHD
- 07 Enhancing Quality of Life and Wellness
- 09 Thriving With cGVHD: Embracing Care, Adherence, and Support
- 10 Navigating Everyday Challenges: Living with cGVHD
- 11 Symptoms Checklist
- 13 Key Messages

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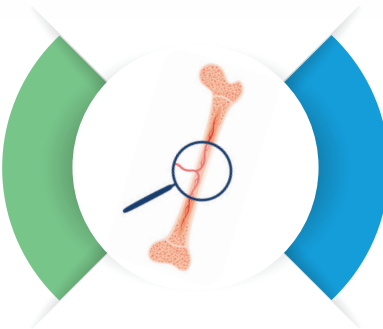
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Bone marrow transplant

Bone marrow transplant involves receiving healthy blood-forming cells from the bone marrow of donors.¹



It is needed in patients who lose the ability to restore blood-forming cells due to blood disorders or autoimmune disorders.¹

The period after transplant is "vigilant" as your body is susceptible to multiple infections.²

Long-term follow-ups are needed for those undergoing bone marrow transplants.^{2,3}



Did you know that...

A multi-disciplinary team will take care of you, including pulmonologists, cardiologists, ophthalmologists, and orthopedic doctors.²

What are the essential steps to safeguard your health after bone marrow transplant?³



Use masks and proper hand hygiene for 6 months after transplant and immunosuppression.^{3,4}



Use a separate room and bathroom for 6 months to avoid exposure to infections from visitors.^{3,5}



Avoid contact with people who have fever, cough, flu, and other contagious infections.³



Cook your food thoroughly and avoid unfiltered water.³

What is GVHD?

Graft-vs.-host disease occurs when the immune cells of the tissue you receive (graft) recognize your body (host) as foreign and launch an attack resulting in many symptoms.^{6,7}



Donor



Graft



Host

How many bone transplant patients are affected by GVHD?

Did you know that...

Even when the matched donor is a sibling, **1 in 2** bone marrow transplant patients can get affected by acute GVHD, and the occurrence is higher in unmatched donors.⁶

Which factors increase the risk of developing cGVHD?

Gender disparity



A gender disparity between the donor and the host (e.g., male-to-female transplant)

Prior GVHD



Being affected by acute GVHD previously

Age



Older age of either donor or recipient

Parity of female donor



A female donor who has given multiple births can be a risk factor.

The risk of cGVHD increases with any of these factors:⁸

What are the basics of cGVHD occurrence?



When does cGVHD occur?



GVHD is a post-transplant complication where donor immune cells attack the recipient's tissues, involving various cytokines and immune cells.⁶



cGVHD typically develops **100 days after** a transplant, with symptoms such as fever and skin rashes.^{6,7}

Factors determining the occurrence and severity of GVHD

Increased severity of GVHD⁶



Donor–host factors such as unmatched transplants and specific protein mismatch



High-dose chemotherapy



Full-body radiation

Reduced severity of GVHD⁶



Use of frozen bone marrow or blood from the umbilical cord



Triple-drug therapy using cyclosporine, methotrexate, and prednisone is more effective than double therapy with cyclosporine and methotrexate.



Living With cGVHD

What is it like to live with cGVHD?⁹

01

Inflammation leading to tissue damage

Numerous inflammatory reactions in response to acute GVHD damage the organs

02

Chronic inflammation

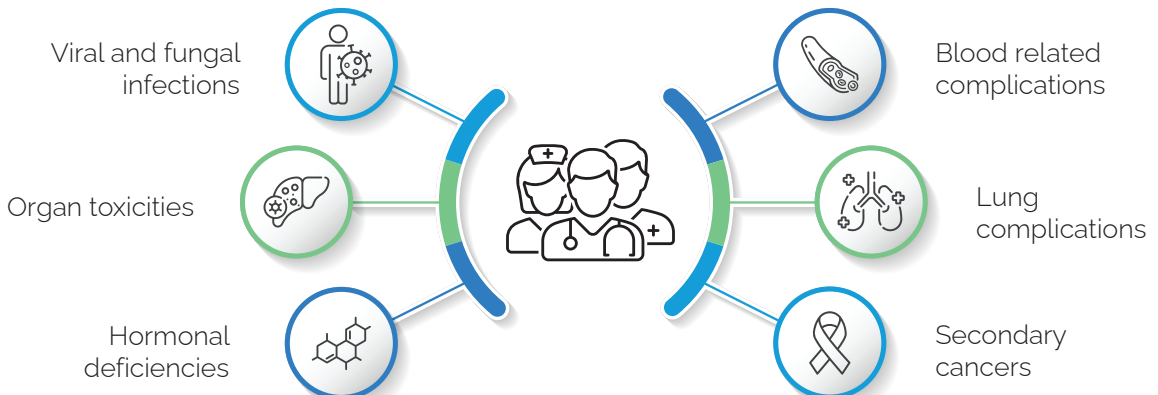
Leading to further inflammation and damage to organs

03

Irreversible injuries

Organ injuries cannot be repaired at this stage

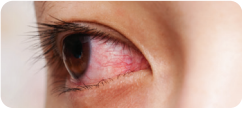
What are the further complications associated with cGVHD?¹⁰



Did you know the signs and symptoms of cGVHD?¹¹



It is important to let your doctor know of any of these symptoms immediately. Please refer to the checklist at the back of the booklet for help.



Eyes

- New onset dry, gritty, or painful eyes
- Swelling and scarring in the conjunctiva
- Dry eye syndrome
- Corneal swelling



Stomach/Intestine

- Growth or membrane inside the esophagus
- Strictures in or narrowing of the esophagus



Genitals

Itchy, firm, shiny red or purple bumps
White, thickened, and crinkly patches

Females: Vaginal scarring or fusion of the skin around the vagina

Males: Difficulty in retracting the foreskin, urethral scarring, narrowing of urethra



Mouth

- White patches
- Redness
- Swelling



Skin

- Reddish-brown spots on neck and cheeks
- Itchy, firm, shiny red or purple bumps
- Tight, hard and waxy skin
- White, thickened, and crinkly patches



Scalp and body hair

- New onset reversible or irreversible hair loss
- Loss of body hair
- Scaling



Lungs

- Blocked and swollen airways in the lungs, bronchioles and its consequences



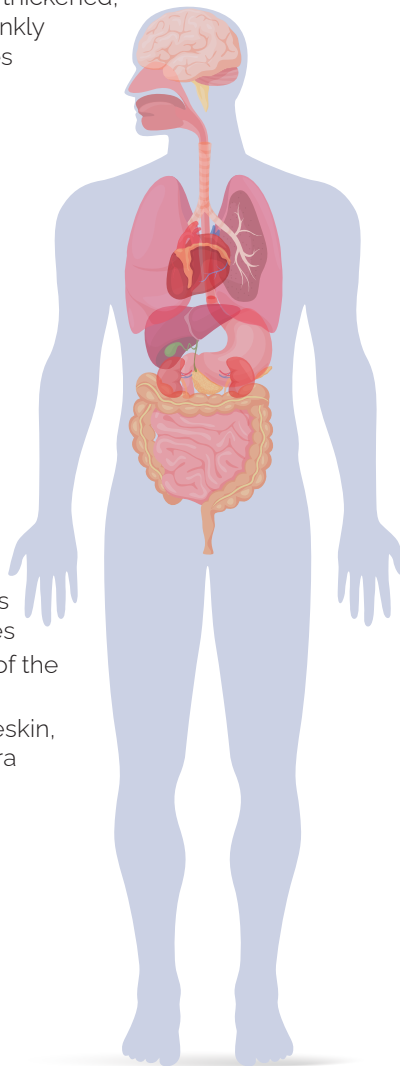
Nail

- Change in shape, color, texture and growth
- Ridging, splitting or brittle features
- Separation of nail from skin
- Abnormal nail bed
- Nail loss



Joints, fascia, and muscles

- Heel pain
- Joint stiffness
- Contractures after heel pain or tissue hardness or stiffness



Precautions to be taken to prevent cGVHD

cGVHD can be prevented by protecting yourself from acute GVHD. Here are some preventive measures:⁶

Protect your skin by using a moisturizer and sunscreen. Avoid scratching and wear protective clothing.



Maintain good dental hygiene.

Be cautious with your diet and avoid foods that can upset your stomach, such as spicy food.



Practice good hygiene, avoid sources of infection, and wear masks when going out.

Get vaccinated against influenza and pneumococcus. This applies to both patients and caregivers.



Enhancing Quality of Life and Wellness

Managing cGVHD

Here are some treatment options available for GVHD.



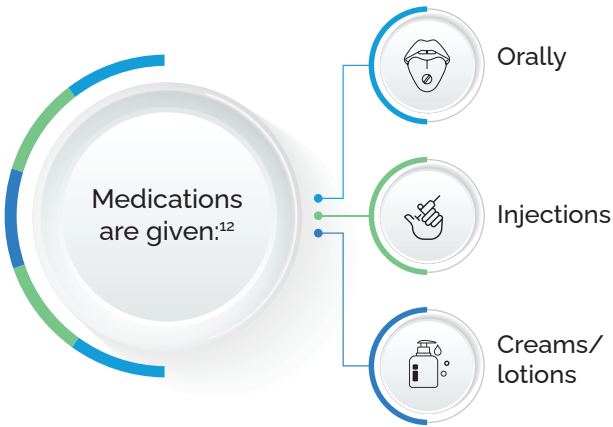
After the transplant, you will be given preventive (prophylactic) medications to suppress your immune system. This will prevent the donor immune cells from launching an attack against your tissues.⁶



Corticosteroids are the most commonly prescribed drugs after a bone marrow transplant.⁶

Treatment for GVHD depends on the type of disease—acute or chronic.¹²

Acute GVHD is treated with increasing doses of medications that suppress your immune system from being too active, usually corticosteroids.¹³



The treatment also varies depending on the affected organ.^{12,13}

cGVHD is managed using treatments that suppress the immune system for a long time. Other treatments that your doctor may recommend include ruxolitinib, belumosudil, ibrutinib, and photopheresis.¹³

Managing emotional health

It is important to seek professional support to help deal with the impacts of cGVHD.¹³



Social workers



Psychiatrists



Psychologists

Join support groups where you can discuss and support others who are going through the same journey as you.¹⁴

Caregivers should also join support groups to better understand how they can help.¹⁴

Maintaining a good lifestyle via exercise, yoga, and meditation can help you cope with GVHD.¹⁴



Increase strength and stamina



Improve the quality of sleep

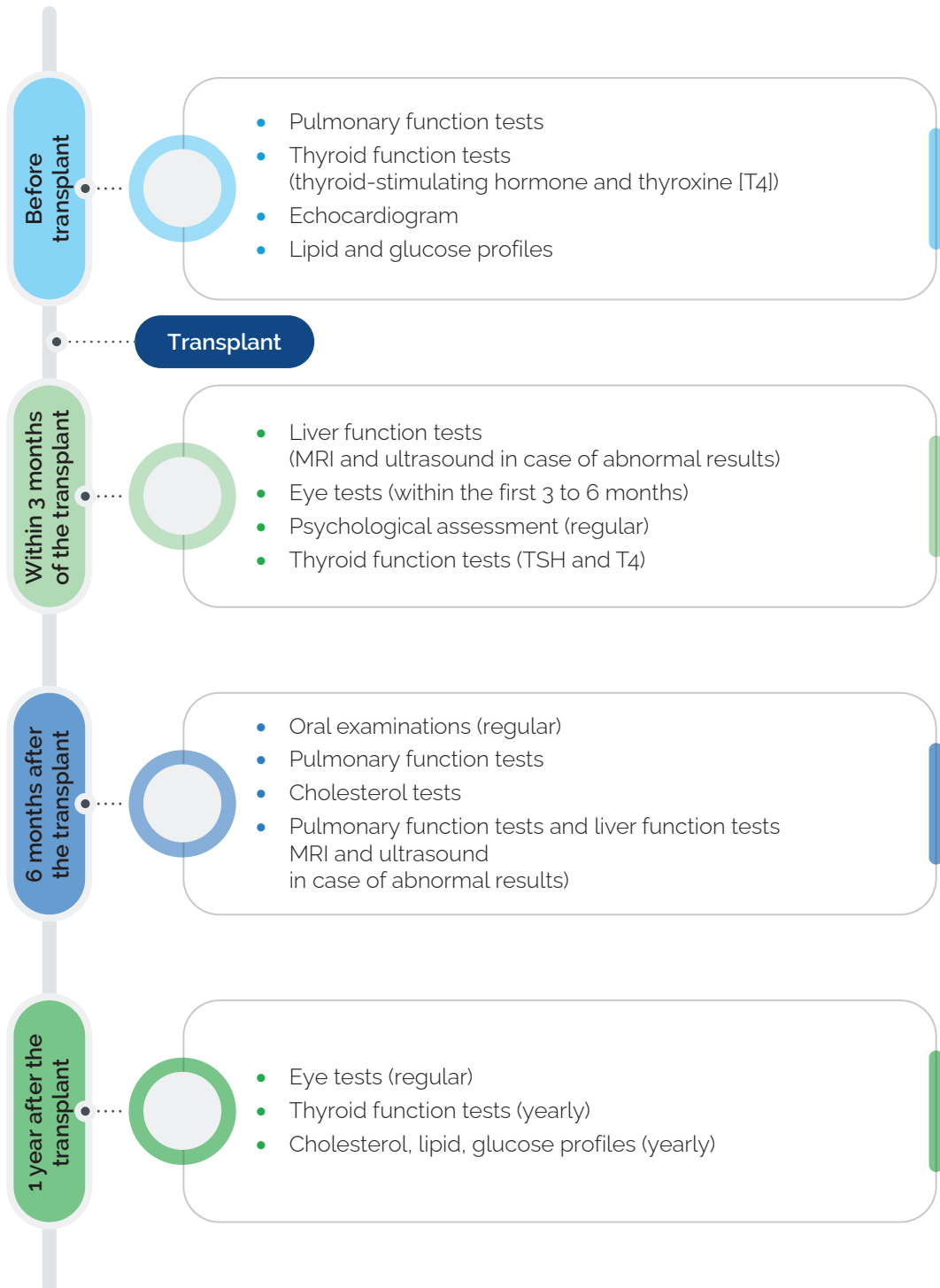


Reduce fatigue and anxiety



Thriving With cGVHD: Embracing Care, Adherence, and Support

You can support your doctor in the long-term monitoring of GVHD by adhering to these tests and check-ups at regular intervals before and after a bone marrow transplant.¹⁵



cGVHD: Chronic graft-vs.-host disease; GVHD: Graft-vs.-host disease; MRI: Magnetic Resonance Imaging; TSH: Thyroid Stimulating Hormone; T4: Thyroxine.



Navigating Everyday Challenges: Living with cGVHD

Quick tips for day-to-day life with cGVHD



While cGVHD can be a long fight, it need not be challenging with the right support.¹⁶



Seek counseling and help from your family and friends to help in your recovery.¹⁷



Creams and lotions prescribed by your doctor will help you overcome skin issues.¹⁷



Light-intensity exercises will help you overcome physical difficulties and improve your range of movement.¹⁷



Your doctor and nurse can help you find assistance in managing your finances, work, and childcare issues during the diagnosis.¹⁷

Adherence to medication



An essential part of recovery after a bone marrow transplant and preventing cGVHD is treatment adherence.

Be aware of the factors that might affect medical adherence and seek help to ensure rapid recovery from cGVHD.



Symptoms Checklist

If you are a caregiver or a patient, the following checklist for symptoms can be prepared before a doctor's visit.^{18,19}

Select what best describes your symptoms:

01

Skin

- Reddish-brown spots Itchy and purple bumps White and thick patches
 Others _____

02

Mouth

- White patches Redness Swelling
 Others _____

03

Eyes

- Dryness Teary eyes Redness
 Others _____

04

Stomach and intestine

- Nausea Stomach pain Diarrhea
 Others _____

05

Joints, fascia, muscles

- Heel pain Joint stiffness
 Others _____

06

Lungs

- Cough Shortness of breath
 Others _____

07

Genitals

- Redness Itching White patches
 Others _____

08

Scalp and body hair

- Hair loss Loss of body hair Scaling

How do I conduct daily activities while living with cGVHD?

What resources can I access to get support for my mental and emotional needs?

Can I go outside while living with cGVHD?

Additional points for discussion



Key Messages



Bone marrow transplant involves transferring healthy blood cells from a donor to a host. The “graft” from the donor may often attack the “host,” resulting in a condition called GVHD.



cGVHD occurs 100 days after your bone marrow transplant and may affect multiple organs in your body, including your skin, stomach, joints, and nervous system.



Therapies to control your immune system will be given to control cGVHD symptoms.



With the help of your caregiver, you should protect yourself from infections.



You would be advised to seek help as much as possible from your friends, peers, caretakers, and other members of your support system.



Keep a checklist of your symptoms to present to your doctor during check-ups.



Caregivers should assist cGVHD patients in their day-to-day activities. They need to ensure medication adherence and also focus on their own mental and physical well-being.

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cGVHD Calendar

Here is a cGVHD calendar for you to clearly see the timing of your next follow-up. A blank calendar is provided to record all your symptoms after speaking to your physician along with a personal checklist.



Month/Year

	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Comments
Mon								
Tues								
Wed								
Thu								
Fri								
Sat								
Sun								

Follow-up Date: _____