

NIH Clinical Center Patient Education Materials

GVHD (Graft-Versus-Host Disease): A guide for patients and families after stem cell transplant

The immune system is the body's tool that fights infection and disease. It works by seeing harmful cells as “foreign” and attacking them. When you receive a donor's stem cells (the “graft”), the stem cells recreate the donor's immune system in your body (the “host”).

Graft versus host disease (GVHD) is the term used when this new immune system from the donor attacks your body. Your donor's cells see your body as “foreign” and attack it, which causes damage. GVHD can range from mild to moderate to severe.

Acute GVHD usually occurs within the first 100 days after your transplant or infusion of T-cells (in a donor lymphocyte infusion, or DLI). Acute GVHD commonly affects your skin, liver, and gastrointestinal (GI) tract.

Chronic GVHD can happen 60-100 days after transplant and can reoccur for several years after transplant.

What are the signs and symptoms of GVHD?

First, make sure to report all new or worsening symptoms to your NIH Clinical Center doctor.

Skin GVHD

- Red rash
- Itching
- Darkening of skin

Liver GVHD

- Elevated liver enzymes determined through blood tests
- Yellowing of the skin and whites of the eyes
- Abdominal pain

Gastrointestinal (GI) GVHD

- Watery diarrhea
- Stomach cramps (especially before and during bowel movements and after eating)
- Persistent nausea

Can I prevent GVHD?

The medical team cannot predict if you will get GVHD.

Depending on the type of stem cell transplant that you have, your doctor may give you medications to lessen the chance of getting GVHD. These medications suppress your new immune system so that it will not attack your body's cells.

You play an important role in helping the medical team prevent GVHD by taking your medications and protecting yourself from the sun.

1. Take the medications prescribed for you after your transplant. Medications such as cyclosporine, tacrolimus, and sirolimus, suppress your immune system to make GVHD less severe. You may need to take these medications for several months after your transplant. It is important to take these medications as prescribed and to report any side effects. If you are unable to take your medications for any reason, or if you have any changes in your skin or in your bowel movements, report that information to your medical team as soon as possible. You will be at greater risk for infection while you take these medications.
2. Protect yourself from the sun. Sun exposure can trigger GVHD or make it worse. When you go outside, wear a hat, long sleeves, long pants, and sunscreen. The best protection is to avoid being out in the sun.

How is GVHD diagnosed?

Your doctor can diagnose GVHD from your symptoms, as well as from results of laboratory tests and tissue samples. The early symptoms of GVHD are often the same as some side effects and complications after a transplant, so diagnosing GVHD can be hard. Before your doctor can make a diagnosis, your medical team will first make sure that there are not other reasons for the symptoms. You can help your medical team by immediately reporting changes in your symptoms or about the onset of new symptoms.

How is GVHD treated?

The goal of GVHD treatment is to lower the graft's immune response against your body, so you will be given medication to do this. Steroids, such as prednisone and methylprednisolone, are medications commonly used. Other medications that lower the immune response, like tacrolimus and sirolimus, are also used. Your treatment may be medications that you take by mouth or put on your skin or an infusion through a vascular access device. Also, treatment may either be outpatient or inpatient. All of these are determined by the severity of your symptoms and concern for complications.

You will be at greater risk for infection while you take steroids. Medications can also cause high blood pressure and other issues. So, along with medication for GVHD, your doctor may admit you to the hospital if you cannot manage your symptoms at home.

How can I manage GVHD symptoms?

Along with your treatment plan, there are also things that you can do to help manage GVHD.

Skin care

- Avoid scratching.
- Use moisturizing lotion. Avoid perfumed lotions.
- Use sunscreen with SPF 30 or greater, and reapply every 1-2 hours while outside.
- Avoid prolonged sun exposure.
- Wear a hat.
- Wear long sleeves and pants.

Diarrhea

- Follow the diet prescribed by your doctor and dietitian to prevent worsening diarrhea.
- Avoid spicy foods.
- Avoid skin problems (such as irritation) around your rectal area. It is very important to keep this area clean. Cleanse this area well after each time that you have diarrhea. Tell your nurse if this area gets red, cracked, painful, or infected.

Preventing infection

- Wash your hands often.
- Stay away from sick family members and friends.
- If your medical team suggests that you wear a mask that covers your nose and mouth, then wear one.

Questions?

If you have any questions about GVHD, feel free to ask your nurse or doctor.

This information is prepared specifically for persons taking part in clinical research at the National Institutes of Health Clinical Center and may not apply to patients elsewhere. If you have questions about the information presented here, talk to a member of your health care team.

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