

# Fast Facts: Living with chronic GVHD

**Living with chronic graft-versus-host disease (GVHD) can be stressful. It's helpful to focus on positive ways to cope with the disease during treatment and recovery.**

## Read on to learn about:

- What to expect with chronic GVHD treatment
- Ways to take care of your health and improve your quality of life
- Tips to manage financial and employment issues during treatment

## What medicines do I need

- The main treatment for chronic GVHD is often steroids. Prednisone is a commonly used one. Steroids and most medicines to treat chronic GVHD hold back (suppress) your immune system.
- You may need medicines to help prevent infections and to help manage side effects from treatment. These include medicines to control blood pressure or blood sugar, prevent stomach irritation or strengthen your bones.
- If prednisone doesn't work for you or you can't take high doses of it, your doctor may recommend another treatment. There are many other options.

## How long will I get treatment?

- The length of treatment is different for each person. You may need treatment for months to years. Your transplant doctor will decide how long you'll get treatment.
- What treatments you get and how long you get them will depend on how the GVHD is affecting your body. You may also need to see many doctors and specialists for a long time.
- It's common for symptoms to worsen when your doctor lowers the doses of your medicine. Tell your doctor about your symptoms so together

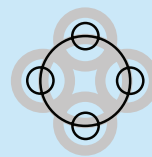
you can find the right doses for you.

- Don't stop or change treatment without talking with your doctor first.

## How can I take care of my health?

- Learn about your medicines and their side effects. Talk to your doctor about any new treatments. Asking questions can help you and your doctor decide what the right treatment is for you.
- Eat a healthy diet. Cut back on salt and sugar. Be sure to get plenty of calcium.
- Drink water.
- Exercise and stretch regularly.
- If you have chronic GVHD of the skin and deeper tissues, ask your doctor if seeing a physical therapist could help.
- Visit an eye doctor, a dentist and skin doctor regularly to watch for early signs of mouth and skin cancer.
- Avoid smoking and excessive alcohol use.
- Wear protective hats and clothing to protect your skin from the sun.
- Ask your doctor if you need any vaccines.
- Report any new symptoms to your doctor right away. Chronic GVHD can also cause new symptoms, even many years after you start treatment.

The information in this fact sheet was developed jointly by Be The Match and the Chronic Graft Versus Host Disease Consortium..



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## What can I do about employment and financial issues?

- Talk to your doctor to see if you're able to go back to work.
- If you can't go back to work because of chronic GVHD, talk to your employer's human resources (HR) department. Ask about resources they may have, such as health and wellness, employee assistance, disability management, or return-to-work programs.
- Tell your doctor if you have trouble paying for your medicines.
- Financial assistance may be available to help with treatment costs.
- Talk to a social worker or financial counselor at your transplant center. They can help you find resources and support to deal with financial or employment concerns.
- Employment help is available from many public and nonprofit organizations such as:
  - Cancer Legal Resource Center at [CancerLegalResources.org](https://www.cancerlegallaw.com/)
  - The U.S. Office of Disability Employment Policy at [dol.gov/odep](https://www.dol.gov/odep)
- Call the Be The Match® Patient Support Center at 1 (888) 999-6743 or email [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org). We offer:
  - Financial grants for patients who demonstrate financial need and meet eligibility criteria
  - Help accessing resources

## What can I do to improve my quality of life

- It's natural and common to feel sad, frustrated and angry. It can help to talk with others about your situation. Consider joining a support group or talking to a counselor. It may help to know you're not alone.
- Look forward to things that you enjoy or different ways to relax. Also, be as active as you can. Staying active may improve your overall coping and emotional wellbeing.
- Tell your health care team if you have distress, anxiety, or sexual problems. They can connect you to resources or people who can help.
- Talk to a counselor. They can help you resolve problems related to GVHD and improve your coping skills and quality of life.
- For free telephone counseling, contact NMDP<sup>sm</sup> Counseling Services at 1 (888) 999-6743 or email [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org). Or, learn more at [nmdp.org/Counseling](https://nmdp.org/Counseling)

## Resources to learn more

Be The Match has a variety of free resources to help you cope with GVHD after transplant. Visit [nmdp.org/patientGVHD](https://nmdp.org/patientGVHD) to find resources that best meet your needs.

Here are some you might find helpful:

- VIDEO: What is GVHD?
- WEBCAST: Living Now – Your Role in Managing Your Chronic GVHD



### At every step, we're here to help

NMDP® has a team dedicated to providing information and support to you before, during, and after transplant. You can contact our Patient Support Center to ask questions you may have about transplant, request professional or peer support, or receive free patient education materials.

Call: 1 (888) 999-6743 | Email: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org) | Web: [NMDP.org/one-on-one](https://nmdp.org/one-on-one)



Every individual's medical situation: transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.