FIND CURES. SAVE LIVES.

Fast Facts: Chronic GVHD of the Skin and Deeper Tissues

Learning more about graft-versus-host disease (GVHD) can help you make informed decisions and manage symptoms.

This fact sheet tells you:

- What chronic GVHD of the skin is
- How to ease symptoms
- How it can be treated
- When to call your doctor

What is chronic GVHD of the skin?

Chronic GVHD of the skin happens when the donor's cells attack your skin. It is the most common type of chronic GVHD.

Chronic GVHD of the skin can cause color changes (red, pink, purple, brown, or white), thinning or thickening, hardening, rashes, scaly areas, bumps, sores or blisters (small pockets of fluid). The skin may itch, feel like a sunburn, feel "woody" like a stick, or you may have a pulling or tightening feeling underneath your skin.

Sclerotic chronic GVHD is a specific type of skin GVHD. This form of skin GVHD causes thickening, tightness, and hardening of the skin and deeper tissues. Sclerotic chronic GVHD is more common on arms, legs, lower belly and lower back. But it can happen anywhere. Sclerosis on the belly may make it harder to take a deep breath. Some people with sclerotic chronic GVHD have difficulty moving their joints. Sclerotic chronic GVHD may cause skin sores to heal slowly.

How can I decrease symptoms?

 If your skin is dry, keep it moisturized. This will help to keep your skin flexible and ease itching. Apply moisturizer right after you shower or bathe to keep moisture from the water in your skin. Ointments and creams are better than lotions.

- If your skin or tissues are tight, gentle stretching exercises, massage, or physical therapy may help loosen the tightness. These activities should be gentle and not hurt much, otherwise you may be causing more irritation that could worsen GVHD.
- Avoid the sun, particularly during peak hours of ultraviolet radiation (10am-4pm). Use sunscreen and wear sun protective clothes. Sun exposure can worsen chronic GVHD and cause skin cancer and wrinkles.
- If you have sores on your skin, keep the sores clean and protected from further injury. Ask your doctor if bandages or medicines applied to your skin may help.
- Avoid positions that decrease blood flow to your legs (for example, crossing your legs or sitting for a long time).

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



What treatments are available?

- Prescription immunosuppressant medicines (medicines that hold back your immune system) that you take by mouth or by injection for your skin may help reduce inflammation (redness and swelling), decrease sclerosis you already have and prevent new sclerosis.
- Your doctor might also prescribe medicines that you put directly on your skin (for example, corticosteroids, tacrolimus, or pimecrolimus).

These medicines can sometimes ease symptoms, such as itch or rash. But steroids can also cause side effects, like thinning of your skin, so don't use them for longer or on different areas than prescribed.

- If your skin is itchy, anti-itch lotions or antihistamine pills (for example, diphenhydramine, or hydroxyzine) may decrease symptoms.
- Your doctor might prescribe extracorporeal photopheresis (ECP) to treat your chronic GVHD of the skin. ECP is a treatment where blood is removed from you, treated under light, then given back to you.

What else should I know?

- Thickening of your skin and tightness of your deeper tissues may be permanent.
- It's important to tell your doctor about any skin changes and follow their instructions. This will help your skin, joints and tissues stay as healthy as possible.
- People with chronic GVHD have a higher risk of skin cancer. See your doctor regularly and report any changes in the color or texture of your skin. For example, you should tell your doctor about a sore that doesn't heal or a new bump in your skin.
- You cannot spread GVHD of the skin to other people.

When should I call my doctor?

- Your skin symptoms worsen
- You have less joint flexibility
- You notice any new bumps or changes in your skin.

Resources to learn more

- For information and help coping with GVHD, contact a BMT Patient Navigator at 1 (888) 999-6743.
- For help finding and joining GVHD clinical trials, contact a Clinical Trials Navigator at 1 (888) 814–8610.

At every step, we're here to help

NMDPSM 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 | Web: 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.