

FAST FACTS: CHRONIC GVHD OF THE SKIN AND DEEPER TISSUES

Learning more about your disease and treatment options can help you make informed medical decisions.

READ ON TO **LEARN ABOUT:**

- Chronic graft-versus-host disease (GVHD) of the skin and deeper tissues
- How to ease symptoms of thickness or tightness due to chronic GVHD of the skin
- How chronic GVHD of the skin can be treated
- When to call your doctor

WHAT IS **CHRONIC GVHD** OF THE **SKIN?**

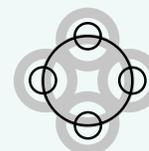
- Chronic GVHD of the skin happens when the donor's cells attack your skin. It is the most common type of chronic GVHD.
- Chronic GVHD of the skin can cause color changes (red, pink, purple, brown or white), thinning or thickening, hardening, rashes, scaly areas, bumps, sores or blisters (small pockets 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. "Sclerotic" means thickening. This form of skin GVHD causes thickening, tightness, and hardening of the skin and deeper tissues. Sclerosis can also make it hard to move your joints.
- Sclerotic chronic GVHD is more common on arms, legs, lower belly and lower back. But it can happen anywhere. Sclerosis in the belly may make it harder to take a deep breath, or may decrease your appetite because you feel full sooner.
- Some people with sclerotic chronic GVHD have difficulty moving their joints. You might notice this more in your wrists, elbows, shoulders and ankles.
- Sclerotic chronic GVHD may cause skin sores to heal slowly. Skin sores are more common on the legs.

WHAT CAN I DO TO **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 sclerosis. These activities should be gentle and not hurt much, otherwise you may be causing more irritation that could worsen GVHD.
- Stay out of the sun. Use sunscreen and wear sun-protective clothes. Sun exposure can worsen chronic GVHD and cause skin cancer and sun damage.
- If you have sores on your skin, keep the sores clean and dry. 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).

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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 OTHER 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 topical immunosuppressive medicines that you rub on your skin (for example, corticosteroids, tacrolimus or pimecrolimus). These medicines can sometimes ease symptoms, such as itch or rash. But they may 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 his or her 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 by touching.

WHEN SHOULD I CALL MY DOCTOR?

- Your skin symptoms worsen
- You're less able to move your joints
- You notice any new bumps or changes on your skin

OTHER RESOURCES TO HELP YOU LEARN MORE

Be The Match® has a variety of free resources to help you after transplant.

Visit BeTheMatch.org/patient-survive and choose the resources that best meet your needs.

Here are some you might find helpful:

- TOOLKIT: *After Transplant Care Guidelines*
- WEBCAST: *Living Now—Your Role in Managing Your Chronic GVHD*

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AT EVERY STEP, WE'RE HERE TO HELP

Be The Match has a team dedicated to providing information and support to you before, during, and after transplant. You can contact us 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: BeTheMatch.org/patient-survive



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.