

Take an Active Role in Your Care: Communicate Your Symptoms to Your Healthcare Team

- Chronic graft-versus-host disease is a condition that develops when donor cells (called the *graft*) attack the organs and tissues of the patient who received them (or the *host*)
- Chronic GVHD may occur at any time after transplant, but most patients develop symptoms after 100 days post transplant. The organs most commonly affected are the skin, mouth, gastrointestinal tract, genitalia, liver, and eyes

GET TO KNOW THESE CHRONIC GVHD–RELATED SYMPTOMS:

Skin/Nails/Hair



- Dryness, itching, tightness (hard to pinch), dimpling, or thickening of skin
- Any color changes (lighter or darker than usual), rashes, scaly or flaky areas, shiny scars, sores, or blisters on your skin
- Thinning of scalp hair, or loss of body hair
- Weak or brittle nails; nail ridges
- Inability to sweat or keep body warm

Joints



- Difficulty in bending or stiffness/pain in your arms, wrists, fingers, or other joints
- Muscle pain, cramps, or weakness in your joints and muscles

Eyes



- Dry or itchy eyes
- Gritty or sandy eyes; excessive crustiness in the morning
- Sensitivity to light or wind (eg, bothered by indoor light or wind from the ceiling fan)
- Excessive tearing
- Blurred vision

Lungs



- Shortness of breath after mild activity (eg, climbing one flight of steps); inability to take deep breaths; or difficulty getting breath out
- Decreased stamina or trouble walking distances that were previously managed without stopping

Mouth



- Difficulty swallowing or opening mouth wide; food or pills get stuck
- Persistent dry mouth; altered taste; redness, ulcers, sores, or bumps in the mouth
- Sensitivity to spicy or acidic food, hot food or drink, soda, or toothpaste

Gastrointestinal Tract



- Abdominal discomfort, cramping and bloating, nausea, vomiting, or changes in appetite
- Diarrhea or changes in the number or consistency of bowel movements that don't improve over time
- Unexplained weight loss (such as recent changes in how clothes fit)

Genitals



- Dryness, burning, itching, sores, or pigmentation changes
- Changes in appearance (eg, redness, white thick skin)
- Discomfort during sexual activity, urination, gynecologic examination, or when wiping the area

Talk to your healthcare professional within 1-2 days of occurrence, about new or changing symptoms you may be experiencing, even if you think they are not related to chronic GVHD. Remember, chronic GVHD may occur at any time, even years, after transplant.



Share Your Symptoms

Please help us care for you. First, fill out the blue box. Then, provide more details by answering on the right. No symptom is too small, so there are multiple sections if you're experiencing more than one.

Check all symptoms that apply:

- Hair loss
- Dry or gritty eyes
- Brittle nails
- Red or dark skin patches
- Rash
- Coughing/wheezing
- Joint stiffness
- Pain
- Mouth sores
- Other

Please confirm the location of the symptom(s) (check all that apply):

- Hair
- Nails
- Eyes
- Mouth
- Chest
- Skin (please specify where)
- Joints
- Genitals
- Stomach
- Other

Please specify the time and date the symptom(s) first occurred:

..... / / ;
Month Day Year
..... : AM/PM
Time event occurred

If I were to further describe this , it felt or looked like

(Name of symptom)

..... I experience it

(Describe the symptom)

(Describe the frequency. Is it constant or intermittent?)

When the symptom first began, I was

(Share what you were doing when the symptom first occurred)

worsened when

(Describe the activities and/or specific times when the symptom felt worse)

If I were to rate the severity of the symptom from 1 to 7, 1 being mild and 7 being severe, I'd give it a

(1-7)

This symptom has affected my ability to

(Share details of the impact the symptom has had on your life and day-to-day activities)

Example: tie shoes, wear contact lenses, eat spicy food, fold clothes, drive a car

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Contact your healthcare team if you start to experience any new symptoms or changes to existing symptoms.