



Talking to your doctor about your chronic GVHD

*A guide to help you get the most from
your office visits and treatment*



Includes a printable symptom tracker

Before your visit

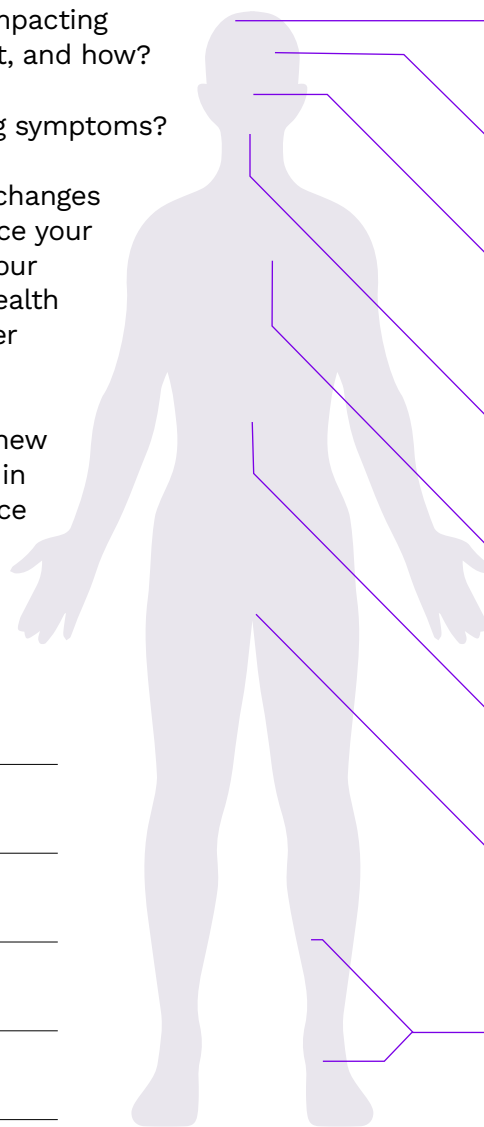
Tracking your chronic GVHD symptoms



Consider this image as you analyze how you're feeling. Then, on the following page, write down your symptoms and their severity each day. Over time, these notes may reveal trends in your chronic GVHD symptoms that you can share with your healthcare team. Being open with your doctors will help them understand how you're feeling, which can help you get the most out of your appointments.

Consider the following questions as you fill out the image below and calendar.

- What symptoms are impacting your daily life the most, and how?
- Where are you noticing symptoms?
- Have you noticed any changes in the way you feel since your last visit? Keep both your mental and physical health in mind as you consider this question.
- Have you noticed any new symptoms or changes in existing symptoms since your last visit?



Skin

Have you experienced any changes to your skin since we last spoke? Are you experiencing any hardening of your skin?

Hair

Are you experiencing unusual hair loss or thinning?

Vision

Are you experiencing dry or teary eyes, irritation that doesn't go away, and/or blurred vision?

Mouth

Are you experiencing sores, irritation, or chapped lips?

Lungs

Are you experiencing cough that doesn't go away, shortness of breath, and/or trouble breathing?

Gastrointestinal

Are you experiencing stomach pain, cramping, nausea or vomiting, and/or diarrhea?

Genitalia

Are you experiencing genital irritation or dryness, rash, or pain during intercourse?

Muscles/joints

Are you experiencing pain and stiffness in your joints or muscle pain, cramps, or weakness?

Take notes here

Before your visit

Symptom calendar

Fill out the tracker below, keeping in mind the symptoms you noted on the previous page. Make a note of each symptom, and rate it 1 through 5 to help you track how they change over time.



1

Hardly noticeable



2

Noticeable, but can still do usual activities



3

Uncomfortable, unable to do some activities



4

Very uncomfortable, hard to do any activities



5

Unbearable, unable to do any activities

Week of: _____

	SYMPTOM	SCORE	SYMPTOM	SCORE
SUN				
MON				
TUE				
WED				
THU				
FRI				
SAT				

Before your visit

Questions to think about before meeting with your healthcare team



Use this page to help you keep track of important information and to help you focus your visit on what is most important to you.

- What other healthcare providers (eg, transplant specialist, pulmonologist, primary care physician) are you currently seeing? When was the last time you saw them?

Name: _____ Specialty: _____ Contact: _____

Name: _____ Specialty: _____ Contact: _____

Name: _____ Specialty: _____ Contact: _____

Name: _____ Specialty: _____ Contact: _____

Name: _____ Specialty: _____ Contact: _____

- What medications are you currently taking (both prescribed and over the counter)?

- Why are you coming in for a visit today? Is it a routine checkup or something else?

- What is your definition of success for chronic GVHD treatment?

- Do you feel like your current treatment plan is preventing you from doing anything?

Consider this one carefully!

- **If there is one thing you want from your chronic GVHD treatment that you are not getting now, what would it be?**

During your visit

Questions you may consider asking your healthcare team



Below are some questions that you might find helpful asking your doctor or healthcare team during your visit. Try your best to take notes while speaking with your provider so you can refer to them again later.

- Can you help me with [your symptom] I’m experiencing?
- Is there anything I can do about my symptom(s)? (refer to the figure you filled out on page 2)
- Are there any lifestyle changes I can make that can help manage my symptoms?
- Do my symptoms make a difference in how long it takes for my medicine to start working?
- My symptoms make physical activity more difficult—can anything be done about that?
- I noticed new symptoms after starting my current medication. Is that to be expected? Is there anything we can do about that?
- Are there any other medicines that I should be aware of?

Take notes here

If you are not satisfied by your chronic GVHD treatment plan, speak to your healthcare team about your options.

During your visit

Tips for talking with your healthcare team



Make the most of your time

Doctor's appointments tend to be quick, so it is important to come with an agenda. This guide can help you do that. Make sure you fill out everything before, during, and after your appointment to keep track of your chronic GVHD and to give your healthcare team as much information as possible.

Clarify, clarify, clarify

You may hear words or phrases you are not familiar with during your appointments. Do not be afraid to ask questions to make sure you understand exactly what is being explained to you.

Be communicative and open

Share as much information as you can during your appointments. This will help your team have a more comprehensive understanding of your challenges and how to address them. Using the figure and symptom tracker calendar on pages 2 and 3, respectively, can help with this.

Advocate for yourself

Tell your healthcare team what you're looking for from your treatment. Making your voice heard will help them best understand your needs.

Consider a holistic approach

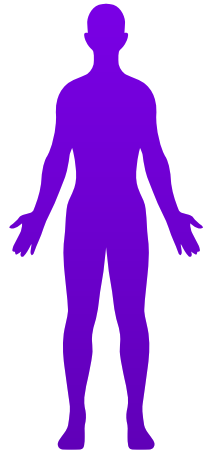
You may receive diet and exercise recommendations that may help you feel better overall. Consider asking them about physical activities to try, or foods that you should add or remove from your menu.

GVHD, graft-versus-host disease.

For use ahead of your visit

Symptom calendar

Continue tracking your symptoms after your appointment. Print out this page as many times as you need to track each week until your next appointment. Doing this can help you track how your symptoms change over time.



1 2 3 4 5

Date of next appointment: _____

	SYMPTOM	SCORE	SYMPTOM	SCORE
SUN				
MON				
TUE				
WED				
THU				
FRI				
SAT				