

Fast Facts: Chronic GVHD of the Lungs

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 lungs is
- How to ease symptoms
- How it can be treated
- When to call your doctor

What is chronic GVHD of the lungs?

Chronic GVHD of the lungs happens when the donor's cells attack the small airways (tubes) in your lungs. This can make your lungs inflamed (red and swollen) and cause scarring.

When this happens, your lungs do not work properly. You might feel short of breath, or less able to exercise. You may have a cough, chest tightness, or feeling like you cannot take a deep breath. In young children they may play less or breathe harder during play.

With chronic GVHD of the lungs, you also have a higher risk of lung infections.

In early chronic GVHD of the lungs, you may not notice any symptoms. Pulmonary (lung) function tests, also called PFTs, are the only tests that can find chronic GVHD of the lungs early. If your doctor thinks you have chronic GVHD of the lungs, you may also need a special CT (or CAT) scan that takes pictures of your lungs when you breathe.

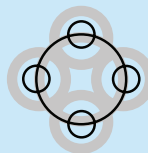
Treatment may work better if your doctor starts it early and before you have symptoms. Ask your doctor about doing PFTs to watch for GVHD of the lungs, especially if you already have chronic GVHD in other parts of your body.

To test your lungs, your doctor may need to do a bronchoscopy. To do this, your doctor takes samples from your airway and lungs using a small tube. They may look for infections that can cause symptoms similar to chronic GVHD of the lungs.

How can I decrease symptoms?

- Lower your risk of infections by:
 - Washing your hands
 - Avoiding sick people, especially those with cold, flu, or lung infections
 - Getting vaccines that your doctor recommends
 - Telling your doctor right away if you have new symptoms, like coughing, shortness of breath, or chest tightness
 - Ask your doctor if it's safe to garden, mow the lawn or do other activities with dirt, soil or plants
 - For children, talk to the doctor about where they can play outside
- Take medicines as directed by your doctor.
- Be as active as you can. Weak muscles will make shortness of breath seem worse. Be patient. Your lungs may not let you be as active as you'd like.
- Lung rehabilitation has helped some people with severe chronic GVHD of the lungs.

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



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What treatments are available?

- Prescription immunosuppressant medicines (medicines that hold back your immune system) or antibiotics for your lungs may help with swelling and scarring.

- Your doctor might prescribe an inhaler. This is a medicine that you breathe into your lungs. Be sure you know how to take your inhalers. If they are taken wrong, they will not work.
- Your doctor might also prescribe medicines used for asthma (such as montelukast) or antibiotics (such as azithromycin).
- Sometimes, doctors prescribe extracorporeal photopheresis (ECP) to treat GVHD of the lungs. ECP is a treatment where blood is removed from you, treated with light, and then given back to you.
- Sometimes chronic GVHD of the lungs gets worse even with treatment. In that case, you may need an oxygen tank to help you breathe. Some patients have had lung transplants.

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?

- Sometimes you might not feel short of breath, but your doctor may still order PFTs. The PFTs help your doctor see how your lungs are working and if you might need treatment.
- Symptoms of chronic GVHD of the lungs are often permanent. The goal of treatment is usually to keep your lungs from getting worse.
- Lung infections, particularly viruses like the flu, seem to make GVHD of the lungs worse. It's very important to protect yourself from infections.
- If you do get an infection like COVID-19 or influenza, let your doctor know because there are treatments for these infections.
- Ask your doctor if you might be eligible to participate in clinical trials (research studies) to treat chronic GVHD of the lungs. Clinical trials help doctors find better treatments for patients in the future.

When should I call my doctor?

- Your shortness of breath gets worse
- You have a fever, or pain when you breathe
- Your phlegm or mucus from your throat isn't clear (for example, it's brownish or greenish)
- Your cough gets worse or you're less able to take a deep breath

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.



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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



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