

FAST FACTS: CHRONIC GVHD OF THE LUNGS

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 lungs
- How to ease symptoms of chronic GVHD of the lungs
- How chronic GVHD of the lungs 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. Chronic GVHD of the lungs can cause coughing, chest tightness or feeling like you cannot take a deep breath.
- 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 (lungs) function tests, also called PFTs, are the only tests that can find chronic GVHD of the lungs early. If your doctor suspects chronic GVHD of the lungs, you may also need a special CT (or CAT) scan that takes pictures of your lungs when you breathe in and out.
- Treatment may work better if your doctor finds and treats chronic GVHD of the lungs early, before you have symptoms. Ask your doctor about doing PFTs periodically to watch for GVHD of the lungs especially if you already have chronic GVHD in other parts of your body.
- To diagnose chronic GVHD of the lungs, your doctor may need to do a bronchoscopy. This procedure lets your doctor take samples from

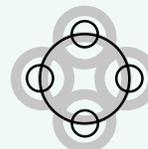
your airway and lungs using a small tube. Your doctor may look for lung infections that can cause symptoms similar to chronic GVHD of the lungs.

WHAT CAN I DO TO **DECREASE SYMPTOMS?**

- Lower your risk of infections by:
 - Washing your hands
 - Avoiding sick people, especially those with cold, flu or lung infections
 - Getting vaccines (immunizations) that your doctor recommends
 - Talking to your doctor right away if you have new symptoms, like coughing, shortness of breath or chest tightness
- Ask your doctor if it is safe to garden, mow the lawn or do other activities involving dirt, soil or plants. Some people have gotten lung infections after these activities.
- Take your medicines as directed by your doctor.
- Be as active as you can. Weak muscles will make shortness of breath seem worse. But be patient with yourself, because your lungs may not let you be as active as you'd like.
- Pulmonary rehabilitation has helped some people with severe chronic GVHD of the lungs. During this treatment, specially trained therapists help you breathe better so you can do as much as possible.

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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) for your lungs may help reduce inflammation and decrease scarring.
- Your doctor might prescribe an inhaler. This is a medicine that you inhale (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 for chronic GVHD of the lungs.

WHAT ELSE SHOULD I KNOW?

- 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 decide if you might need treatment.
- Your doctor will measure whether your lungs are getting better with treatment by doing PFTs. PFTs are the best tests to measure GVHD of the lungs.

- 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 is very important to take precautions against infections.
- Ask your doctor if you might be eligible to participate in clinical trials (research studies) for treatment of 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

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.