

Fast Facts: Chronic GVHD of the Vulva & Vagina

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 vulva and vagina is
- How to ease symptoms
- How it can be treated
- When to call your doctor

What is chronic GVHD of the vulva and vagina?

Chronic GVHD of the vulva and vagina happens when the donor cells attack these tissues. The vulva is the outer part of the vagina (birth canal). It commonly happens within 2-3 years after transplant.

People with chronic GVHD of the vulva and vagina may feel dryness, burning or itching. They may develop open sores, cracks, and redness on the vulva or vagina. Some people have external genital (vulvar) pain at rest or when they wear tight clothing. Others have pain with urination, pain with vaginal sex, or bleeding after sex. Symptoms of chronic GVHD of the vulva and vagina can also seem like symptoms of vaginal infection or menopause.

Without treatment, chronic GVHD of the vulva and vagina can cause permanent tissue changes. This could lead to scarring or even complete closure of the vagina.

Doctors need to do a pelvic exam to diagnose this type of GVHD. Sometimes they need to take a small sample of vaginal tissue to look at more closely under a microscope.

How can I decrease symptoms?

- If you are near or have gone through menopause, ask your doctor about using low-dose topical estrogen. Estrogen can be used as a pill, cream or vaginal ring. This is different from hormone replacement therapy where people take estrogen as a pill or patch. Estrogen may ease vaginal dryness and other menopause symptoms.
- Clean your vulva and vagina gently with warm water only. Don't use perfumed washes or lotions in the area, even gentle ones.
- Let soap and water from washing other parts of your body rinse over your vulva. Pat the area dry.
- Wear loose-fitting cotton underwear.
- Don't douche. This can cause irritation and infections.
- Use a water or silicone-based lubricant before vaginal sex. Use one that doesn't have perfumes or dyes or alcohol. Vaginal moisturizers, such as Replens, may also help. Some people find that silicone-based lubricants last longer during sex. Olive or coconut oil lubricants are safe, too.
- Look at your vulva with a handheld mirror every week. Tell your doctor about any changes.
- Have vaginal sex or use a dilator at least once a month. Tell your doctor if you have any pain. You can order dilators anonymously on the internet.

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



What treatments are available?

- The first treatment is usually a strong steroid ointment or gel used 2 times each day for a few weeks. Your doctor will check your symptoms and do pelvic exams often to make sure the GVHD is getting better.
- Avoid steroid creams. They can cause irritation.
- If steroid ointment or gel doesn't heal the GVHD, you may need a topical immunosuppressant medicine. These are medicines, such as Cyclosporine and Tacrolimus, that hold back your immune system). They may cause vaginal burning.
- Dilators or regular vaginal sex can keep your vagina from narrowing or closing.
- If your vagina narrows or closes off, you may need surgery to open the vagina. Even if you aren't sexually active, you'll need regular pelvic exams and Pap smears. After surgery, you'll need to use vaginal dilators regularly.

What else should I know?

- When GVHD of the vagina or vulva is found early, it often gets better quickly with topical medicines. If it isn't treated early, you may have long-term or even permanent changes to your vagina or vulva and your quality of life may suffer.
- Have a doctor with experience doing pelvic exams check your vulva and vagina 3 months after transplant and then yearly, even if you don't have any symptoms. If possible, see a gynecologist with experience caring for people after transplant.

- Tell your doctor about new symptoms right away so they can treat them.
- Vulvar or vaginal infections can be more common during treatment.
- You can't spread GVHD of the vulva and vagina to other people through touching or sex.
- Some people feel embarrassed talking about their vulva or vagina with their doctor. Remember, your doctor wants to help you. It's important to tell your doctor what's happening with your body.
- Tell your doctor if you have lower interest or less satisfaction with sex.
- Other things can cause symptoms that seem like chronic GVHD of the vulva and vagina. Examples include vulvar or vaginal infections and genital atrophy, which is a symptom of early menopause. Tell your doctor about any new symptoms right away.

When should I call my doctor?

- You have new symptoms in your vulva or vagina
- Your symptoms get worse
- You have a fever or other signs of infection
- It's too painful to have vaginal sex or use a dilator
- You have unexpected genital bleeding

Resources for you

- For information and help coping with GVHD, contact a 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.



At every step, we're here to help

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



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.

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