

FAST FACTS: CHRONIC GVHD OF THE VULVA AND VAGINA

Learning more about treatment options for GVHD can help you make informed medical decisions.

READ ON TO **LEARN ABOUT:**

- Chronic graft-versus-host disease (GVHD) of the vulva and vagina
- How to ease symptoms
- How it can be treated
- When to call your doctor

WHAT IS **CHRONIC GVHD** OF THE **VULVA** AND **VAGINA**?

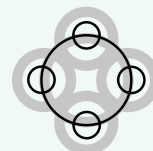
- Chronic GVHD of the vulva and vagina happens when the donor cells attack these tissues. The vulva is the outer part of the vagina (birth canal).
- It commonly happens within a year after transplant. It usually affects the vulva first and then the vagina later.
- People with chronic GVHD of the vulva and vagina may feel dryness, burning, or itching. Some people have pain when they wear tight clothes. Others have pain with urination or vaginal sex. Sometimes people have bleeding after sex.
- Without treatment, it can cause severe pain and make it impossible to have vaginal sex.
- Doctors need to do a gynecological exam to diagnose this type of GVHD. Sometimes they need to take a small piece of vaginal tissue to look at more closely under a microscope.

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

- Ask your doctor about taking estrogen. Estrogen can be taken as a pill, vaginal cream, vaginal ring, or vaginal suppository. Estrogen may ease the dryness or other symptoms of menopause.
- Clean your vulva and vagina gently with warm water only. Don't use perfumed washes or lotions. Wear cotton underwear that's not too tight.
- Use a water or silicone-based lubricant before vaginal sex. Use one that doesn't have perfumes, dyes, or alcohol. Vaginal moisturizers may also help. Some people find that silicone-based lubricants last longer during sex.
- Look at your vulva every week. Tell your doctor if you see any changes.
- Have vaginal sex or use a dilator 2-3 times a week if you don't have pain. This can keep the vagina from narrowing, or even closing. You can order dilators anonymously on the Internet.
- If you have swelling, redness, open sores, or pain, vaginal sex might be uncomfortable or painful. Tell your doctor if you have any of these symptoms.
- Have your doctor check your vulva and vagina 3 months after transplant and then yearly, even if you don't have symptoms. See a gynecologist with experience caring for people after transplant.

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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 TREATMENTS ARE AVAILABLE?

- Prescription topical creams or ointments that have strong steroids in them may help.
- Your doctor may give you topical immunosuppressant medicines (medicines that hold back your immune system). Examples include Cyclosporine, Tacrolimus and corticosteroids. Topical Cyclosporine or Tacrolimus may cause genital burning.
- Dilators or vaginal sex can keep the vagina from narrowing or closing.
- If your vagina narrows or closes off, surgery may be needed so you can have vaginal sex again. After surgery, you'll need to use vaginal dilators or have vaginal sex regularly.

WHAT ELSE SHOULD I KNOW?

- 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 doctors want to help you. It's important to bring up what's happening with your body to your doctor.
- If the problem isn't treated early, you could have long-term problems with vaginal sex and your quality of life may suffer.
- Tell your doctor if you have lower interest in sexual activity or less satisfaction with sex.
- Vulvar or vaginal infections can be more common during treatment for this type of GVHD. These infections include:
 - Herpes - causes open, painful sores

- Human papilloma virus (HPV) - causes warts or abnormal pap smear
 - Yeast - causes cheesy discharge and itching
 - Bacteria - causes discharge
- If you have any of these symptoms, tell your doctor so they can treat it.

- Other things can cause symptoms that seem like chronic GVHD of the vulva and vagina. This may include 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?

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

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-after 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 GHVD*
- WEBCAST: *Living Now—Sexual Health after Transplant*

Most recent medical review completed OCT 2016.



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-after



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.