

Chronic Graft-Versus-Host Disease (GVHD) of the Vulva and Vagina

This handout explains chronic GVHD of the vulva and vagina, how to ease symptoms, treatments and when to call your doctor.

What is chronic GVHD of the vulva and vagina?

Chronic GVHD of the vulva (all external areas of your genitals) and vagina can happen after you have had a bone marrow or stem cell transplant (allogenic transplant). It is when the donor's cells attack the skin around your vulva and inside your vagina.

Usually, this problem starts about 10 months after your transplant. The vulva is usually the first area to show GVHD, and the vagina might show GVHD later.

What are the symptoms I would feel?

If you have GVHD of the genitals, you may feel:

- Dryness
 - Burning
 - Itching
 - Bleeding
 - Pain when you touch your vulva
 - Pain when you pee
 - Pain when you have sex
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What are the signs I might see?

If you have GVHD, you or your doctor might see:

- Redness of your vulva
 - Open sores
 - A break or slit in the skin or inside your vagina
 - Scar tissue on your vulva or in your vagina
 - Lichen planus (lacy white patches or sores)
 - Inflammation or swelling in your vagina
 - Your vagina become narrow or short
 - In its late stages, chronic GVHD of the vulva and vagina can lead to pain and adhesions. Adhesions are when the walls of the vagina stick together, causing the vaginal opening to close.
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To Learn More

- Cancer and Blood Disorders Clinic
206-987-2106
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

How do I know if I have GVHD?

Your doctor will likely be able to diagnose chronic GVHD of the vulva and vagina with your signs and symptoms alone. If they cannot, they may need a biopsy (a tissue sample).

You might feel embarrassed to talk about this with your doctor, but your doctor wants to help you. It is better when this problem is found and treated early. It is important to have your doctor check your vulva and vagina at your 1-year anniversary of transplant, and once a year after that, even if you do not have any symptoms. This problem can develop many years after transplant.

What can I do to decrease symptoms?

- Clean your vulva and vagina gently with warm water only each time you bathe or shower. Avoid soap or lotions that are scented.
- Avoid tight underwear and synthetic fabrics like polyester or nylon.
- Use a water-based or silicone-based lubricant during sex after your transplant. Make sure your lubricant has no added scents or dyes. Vaginal moisturizers may also be helpful.
- Look at your vulva regularly and tell your doctor if you notice anything different.
- Dilators can sometimes be necessary. Ask your doctor if dilators are available or order them online.

How is GVHD Treated?

Prescription medicine

Use these medicines only if prescribed by your doctor:

- Topical (skin) creams or ointments that have strong steroids in them
- Topical immunosuppressive medicines (for example, Cyclosporine or Tacrolimus)
- Estrogen (pills, topical creams, vaginal rings or suppositories)

Surgery

Surgery may be needed if GVHD has caused your vagina to close. If this happens, surgery can sometimes be helpful. After surgery, you may need to use vaginal dilators.

What else should I know?

- Another common problem in women after transplant is genital atrophy. This is when your vulva and vagina experience changes due to lower levels of hormones if your ovaries are no longer functioning due to chemotherapy or radiation. The symptoms for genital atrophy are similar to GVHD, but your doctor can help decide if your symptoms are from atrophy or GVHD. The treatments may be different.
- Vaginal infections (herpes virus, human papilloma virus, yeast and bacteria) are also common after transplant. These infections may have some of the same symptoms as GVHD. Infections can also be more common if you are being treated for GVHD. Tell your doctor if you have any new symptoms. If you have an infection, your doctor will treat you for the infection.

- You cannot spread vaginal GVHD to other people through touching or sex.
- If you are not currently having sex, it is especially important to check your vulva and vagina for signs of GVHD. Even if you have no symptoms it is important to check.

When should I call my doctor?

- Your symptoms of chronic GVHD of the vulva and vagina get worse.
- You have new symptoms in your vulva or vagina.
- You have a fever or other signs of an infection.
- It becomes too painful to have intercourse or use your dilators.

Where can I learn more?

- Be the Match has a variety of free resources to help you after transplant, visit bethematch.org online and choose the resources that best meet your needs. For more information on Chronic GVHD visit bethematch.org/patients-and-families/life-after-transplant/physical-health-and-recovery/graft-versus-host-disease-basics/.