

# **Vulvar Diseases**

An Introduction to Caring for Yourself

**The University of Michigan Center  
for Vulvar Diseases**



**MICHIGAN MEDICINE**  
UNIVERSITY OF MICHIGAN

# Table of Contents:

<b>About the Center for Vulvar Diseases.....</b>	<b>3</b>
Our care team.....	3
Contact information.....	6
<b>Your vulva.....</b>	<b>8</b>
Parts of the vulva.....	8
Checking your vulva for disease.....	9
<b>Vulvar diseases.....</b>	<b>11</b>
Common medical terms and definitions.....	11
Lichen simplex chronicus.....	11
Chronic or recurrent yeast infection.....	13
Lichen sclerosus.....	14
Lichen planus.....	15
Psoriasis.....	15
Paget’s disease.....	15
HPV-related disease.....	16
Hidradenitis suppurativa.....	17
<b>Vulvar pain and vulvodynia.....</b>	<b>19</b>
<b>Vulvar pain treatments and therapies.....</b>	<b>22</b>
Comfort measures.....	22
Vaginal dilators.....	24
Lubricants.....	29
Vaginal moisturizers.....	31
<b>Vulvar diseases and sexual health.....</b>	<b>32</b>
<b>Resources.....</b>	<b>36</b>

# About the Center for Vulvar Diseases

## What is the Center for Vulvar Diseases?

The University of Michigan Center for Vulvar Diseases is a care center founded in 1993. It includes the Vulvar Diseases Clinic, and it provides support for patients with problems of the vulva that are too complex for a primary care gynecologist to test and treat.

## Who is part of the care team at the Vulvar Diseases Clinic?

When you come to the Vulvar Diseases Clinic, you will get care from a team that includes:

- Doctors with special training in vulvar disease
- Doctors in training (fellows and residents)
- Clinical social workers with special training in sexual health
- Nurses
- Medical assistants

You can read more about each role below, as well as read about some of the doctors currently working in the clinic.

## Doctors

### Kathryn Welch, MD (Medical Director)

- Dr. Welch is an Associate Professor of Obstetrics and Gynecology at the University of Michigan. She is a Michigan native who got her medical degree from Wayne State University School of Medicine and completed her obstetrics and gynecology residency at Wayne State University - Detroit Medical Center. She is a member the International Society for the Study of Vulvovaginal Diseases, the American Society for Colposcopy and Cervical Pathology, and The Menopause Society.

### **Hope Haefner, MD**

- Dr. Haefner is the Harold A. Furlong Professor of Women's Health at the University of Michigan. She completed medical school, her obstetrics and gynecology residency, and a gynecologic pathology fellowship at the University of Michigan. She is the past president of the International Society for the Study of Vulvovaginal Disease and the American Society for Colposcopy and Cervical Pathology. Dr. Haefner has been recognized for her teaching as well as her clinical care of patients.

### **Natalie Saunders, MD**

- Dr. Saunders is an Associate Professor in Obstetrics and Gynecology at the University of Michigan. She completed medical school and her obstetrics and gynecology residency at the University of Michigan. She is a member of the International Society for the Study of Vulvovaginal Disease and The Menopause Society.

### **Ebony Parker-Featherstone, MD**

- Dr. Parker-Featherstone is an Associate Professor in Family Medicine and Obstetrics and Gynecology, the Associate Chair for Diversity, Equity, and Inclusion, and the Medical Director of Ypsilanti Family Medicine. She completed medical school, her obstetrics and gynecology residency, and a women's health fellowship at the University of Michigan. She is a member of the International Society for the Study of Vulvovaginal Disease.

### **Angela Liang, MD**

- Dr. Liang is an Assistant Professor in Obstetrics and Gynecology at the University of Michigan. She completed medical school at Wayne State University and her obstetrics and gynecology residency at the University of Michigan.

### **Abby Brown, CNM/FNP**

- Abby Brown is an advanced practice provider (APP). She graduated from Vanderbilt University of Nursing with a dual degree in Nurse-Midwifery and Family Nurse Practitioner.

### **Fellows**

Fellows are doctors who have completed medical school and their residency training in obstetrics and gynecology or family medicine. They are qualified to practice on their own, but they chose to get advanced training in a specialty.

### **Residents**

Residents are doctors who have graduated from medical school and are getting 4 years of advanced residency training in obstetrics and gynecology. Michigan Medicine is a teaching institution where residents are an important part of patient care. They are always supervised by one of the Vulvar Diseases Clinic doctors.

### **Sex therapists**

A visit with a certified sex therapist or counselor is a standard part of care at the Vulvar Diseases Clinic. The certified sex therapists who work in the clinic are clinical social workers who work at Michigan Medicine, the Center for Sexual Health, and in private practice. Current sex therapists on staff include:

- Sara Zocher, LMSW
- Amy Raad, LMSW

### **Nurses**

Nurses are a valuable part of our team. They provide extra education and care coordination.

## **Medical assistants**

Medical assistants are a highly valued part of our team. They are the first people you meet when you come to the clinic. Please share any medical concerns you may have with them, so that we can be aware of your needs.

## **What can I expect after my first Vulvar Diseases Clinic visit?**

Your doctor will talk with you about whether you need a return visit. If you were referred to the Center for Vulvar Diseases by a healthcare provider, we will send a letter to them telling them what we know about the cause of your illness and our plan for care. It is possible that the healthcare provider who referred you will be able to continue your care. If not, we will schedule you for a return visit. Sometimes, we will ask you to call us or send us a message instead of coming back for a visit.

## **What is the contact information for the Vulvar Diseases Clinic?**

You may use the online patient portal ([MyUofMHealth.org](http://MyUofMHealth.org)) to send us a message or reschedule a visit, or you can call (734) 763-6295 on Monday through Friday between 8:00 AM - 5:00 PM.

All messages and calls are first reviewed by a nurse. Generally, they'll be able to respond to your message within 36 hours (3 days). Depending on your needs, they may follow up by:

- Providing medical advice
- Scheduling a visit in the clinic for you
- Refilling a prescription
- Consulting with one of the doctors to make sure you get a reply as soon as possible

## **When should I contact the Vulvar Diseases Clinic?**

You may call or send us a message to:

- **Tell us if there has been a change in your symptoms.** At the end of a visit, we may ask you to contact us after you have been doing the

treatment plan for a certain amount of time (such as 1 month). It is important for you to do this as planned, so we can decide whether the treatment plan should be changed.

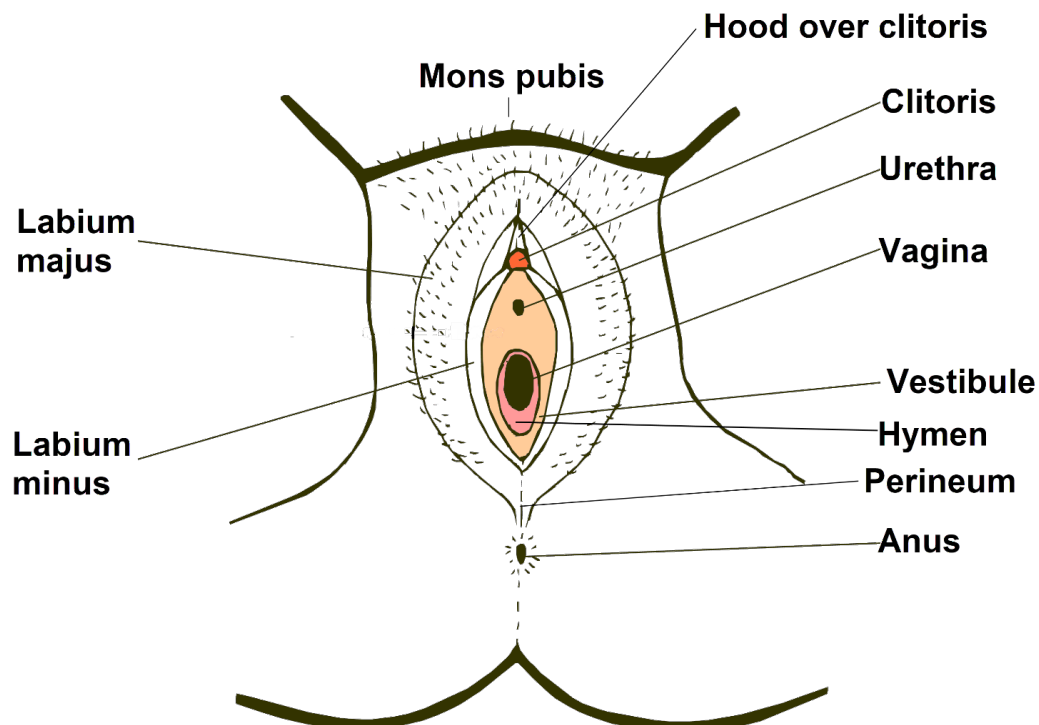
- **Ask for advice** about side effects from a medication or other treatment plan.
- **Tell us if your symptoms are worse, or if you have new symptoms** that you think are caused by vulvar disease.
- **Ask for a prescription refill.** When we send a prescription, the amount of medication you will get from your pharmacy is carefully planned so that you will have enough to last until your follow-up visit at the Center for Vulvar Diseases or your visit with the healthcare provider who referred you. If the date of your follow-up visit changes and you will need a refill before the visit, please tell us before you run out of the medication.
  - Please plan ahead, as it will take about 3 days to get your prescription refilled.
  - Be aware that we do not check messages sent on a weekend until the following Monday.
  - When asking for a prescription refill, make sure you give us the following information:
    - Medication name and dose
    - Your pharmacy name, phone number, and fax number

# Your vulva

## What is the vulva?

The **vulva** is the part of the body for women or people assigned female at birth that includes the external genital parts (parts on the outside of your body that are involved in sex and reproduction). The vulva is located in between your lower stomach and the anus (the opening where poop leaves your body).

The parts of your vulva include the mound of fatty tissue above your pubic bones (**mons pubis**), the large outer lips (**labia majora**), the small inner lips (**labia minora**), the **clitoris** (covered by a hood, or flap of skin), the opening that urine (pee) comes out of (**urethra**), the opening to the vagina (**vestibule**), the thin tissue at the entrance of the vagina (**hymen**), and the skin between the vaginal and anal openings (**perineum**).



Miguelferig, CC0, via Wikimedia Commons



## **How do I check my vulva for disease?**

It is important to find vulvar disease as early as possible, when it can best be treated. Get checked for symptoms such as itching or bleeding, and look at your vulva so you can keep track of any changes that need to be checked by a gynecologist. Some changes can be a sign of cancer, which you should not ignore. **Do a self-exam using a mirror once a month or when you have new symptoms that are concerning.** Use the picture above to help you as you look.

- Just like other parts of your body, you should know what your vulva looks like so you can identify any new change that may need testing or treatment. Every person's vulva has the same parts, but they may look very different. For example, the labia minora (inner lips) may be longer than the labia majora (outer lips) for some people, or shorter for others. The 2 sides of the labia minora may look different. This is all normal.

## **What are the steps for doing a vulva self-exam?**

1. Wash your hands well.
2. Make sure you have good lighting and a hand mirror or magnifying mirror.
3. Get in a comfortable position that allows you to see your vulva. This may be lying down, sitting with your back resting on pillows, squatting, or kneeling.
  - If you have not looked at your vulva before, it may look different than what you expect. This is why it is good to look when you don't have any symptoms, so you know how your vulva looks when it is healthy.
4. Look at the mons pubis, the outside of the labia majora, and the perineum.
5. Gently separate your labia majora and check the inside of the lips and in between the labia majora and minora.

6. Gently separate your labia minora and check the inside of the lips and all the tissue in between, including the urethra (opening from your bladder) and vestibule (opening of the vagina).
7. Gently pull back the hood of the clitoris and check the area under the hood and at the tip of the clitoris.
8. Check the anus and surrounding skin.

### **When should I get my vulva checked by a healthcare professional?**

Schedule a visit at the Vulvar Diseases Clinic if you find any of the following during your self-exam:

- Skin changes that are raised, rough, white, thickened, red, or raw
- Blisters (fluid-filled bumps)
- Moles with any of these features:
  - One half that is unlike the other half
  - Borders that are irregular, scalloped (wavy, like the edge of a seashell), or poorly defined
  - Different colors or thicknesses
  - Larger than a pencil eraser

## Vulvar diseases

This section gives a short description of different vulvar diseases. If you have one of these diseases, we will give you more information about the disease and your treatment plan.

### What are some common medical terms related to vulvar disease?

Definitions for some of the medical terms used in this section are included below. Please refer back to these definitions as you read about your disease.

- **Skin biopsy:** Because different diseases can cause similar symptoms, a vulvar exam often includes a **biopsy** (removing a small piece of skin) for lab testing. We will give you a shot of numbing medication before the biopsy.
- **Inflammation:** The body's response to injury, infection, or disease. Signs of inflammation include heat, swelling, redness, and pain.
- **Chronic:** Lasting a long time.
- **Immune system:** Our body's way to recognize and fight germs that cause disease, harmful substances, and abnormal changes in your body (such as cancer).
- **Autoimmune disease:** A disorder caused by your immune system attacking part of your own body.
- **Oral medication:** Medication that you swallow, such as a pill or capsule.
- **Topical medication:** Medication that you put on your skin, like a cream or ointment.

### Vulvar itching and scratching: Lichen simplex chronicus

#### What are the symptoms?

- Vulvar itching can be caused by many different diseases or skin irritants. A normal response to itching is to scratch or rub the skin. While this may bring relief for a moment, it also irritates the skin and can cause more

itching. This **itch-scratch cycle** can go on for so long that the original cause of itching may be hard to identify.

- **Lichen simplex chronicus** is an area of thickened skin caused by repeated rubbing and scratching from the itch-scratch cycle. The skin becomes red or dark with thick white or gray patches. It often involves the skin on the hood over the clitoris, labia majora, and perineum.

### **What are some causes of vulvar itching?**

Health conditions:

- Eczema
- Psoriasis
- Lichen sclerosus
- Anxiety
- Yeast or fungal infections
- Postmenopausal lack of estrogen
- Lichen planus
- Depression

Skin irritants:

- Urine (pee)
- Stool (poop)
- Wet bathing suits
- Sweat-soaked clothing
- Dyed underwear
- Spermicides
- Neomycin (in antibiotic creams)
- Scented laundry detergent or softener
- Scented toilet tissue, pads, or tampons
- Frequent cleaning with baby wipes
- Frequent washing with soap
- Adhesives in pads or pantliners
- Vaginal lubricants
- Benzocaine (in anti-itch creams or numbing creams)

### **What is the treatment?**

The goal of treatment is to stop the cycle of scratching and itching. We will teach you about vulvar care. Your treatment can include many types of medication, such as:

- Medications to decrease yeast

- Antibiotics to decrease inflammation and treat infection (because scratching can tear the skin and increase the risk of infection caused by bacteria)
- Steroid ointments
- Oral steroid medications
- Steroid injections
- Medications to stop itching
- Medications to cause deep sleep

### **Chronic or recurrent (repeat) yeast infection**

#### **What are the symptoms?**

- Common symptoms from yeast infection include itching, burning, swelling, and a thick white discharge (fluid from the vagina) with clumps that look like cottage cheese.
- People who think they have repeated yeast infections may actually have a different disease (such as a skin condition like lichen sclerosus).

#### **What is the treatment?**

We will look for all possible causes of your symptoms and get a yeast culture (sample) to confirm you do have a yeast infection. We may ask the lab to do tests to find out what treatments will kill the yeast you have. Your treatments may include:

- Creams in the vagina
- Ointments on the vulva
- Pills you swallow
- Boric acid suppositories in the vagina

You may need to use treatment on a schedule for several months in a row to prevent a repeat infection.

## Lichen sclerosis

### What are the symptoms?

- Lichen sclerosis is a chronic skin condition that causes itching, discomfort, and pain. It may involve the entire vulva, from the hood of the clitoris to around the anus. The affected skin:
  - May be fragile (weak) and tear easily
  - Often has a white color
  - Often looks thin, shiny, and crinkled
- Untreated lichen sclerosis can cause scarring and changes in the way your vulva looks. If lichen sclerosis is not treated properly, it can develop into vulvar cancer.
- Chronic inflammation from lichen sclerosis can cause abnormal growth of skin cells called **differentiated vulvar intraepithelial neoplasia (dVIN)** or **HPV-independent precancerous lesions**. If untreated, dVIN can develop into vulvar cancer. Overall, 3 out of 1,000 women will develop vulvar cancer during their lifetime. Treatment with topical steroids lowers the risk of getting precancer and cancer.

### What is the treatment?

Treating the skin with steroid ointments usually relieves the itching. Because lichen sclerosis is a chronic disease, you must continue treatment for a long time to keep your symptoms from coming back, stop chronic inflammation, and prevent scarring. There are other treatments we can try if this does not work.

## Lichen planus

### What are the symptoms?

- Lichen planus is a type of autoimmune disease and skin condition that affects the moist skin that protects the inner vulva, vagina, and inside of the mouth. It causes red, swollen tissue and open sores. When it affects

the vulva and vagina, it causes itching, burning, pain, and inflammation. If untreated, it can cause scarring that narrows or closes the vagina.

- Many people with vulvar lichen planus also have it in the mouth, where it affects the inside of the cheeks, lips, tongue, and gums. There are often painless, white, lacy patches on the inside of the cheeks and lips. Gums can become red, swollen, and painful.

### **What is the treatment?**

Treatment starts with steroid ointments on the vulva and, if needed, steroid cream inside the vagina. There are other treatments if this does not work. Lichen planus is a chronic illness, and after symptoms are gone you will get a plan for ongoing treatment.

## **Psoriasis**

### **What are the symptoms?**

Vulvar psoriasis is a skin disease that causes patches that may be glossy red or gray in color. The skin may develop white or silver scales. Most people with vulvar psoriasis also have it on other parts of their body, but up to 1 in 20 women with psoriasis may have it only on the vulva. Along with a changed look to the skin, it may cause itching or painful skin cracks.

### **What is the treatment?**

There are many treatments for psoriasis. We will work with you and your dermatologist to find the best treatment for you.

## **Paget's disease**

### **What are the symptoms?**

Paget's disease causes slightly raised, red patches of skin with itching or burning pain. Paget's disease is a slow-growing cancer on the top layers of the skin that affects the vulva. In rare cases, Paget's disease may be related to other

cancers in the body. We will talk with you about what kind of testing you need at your clinic appointment.

### **What is the treatment?**

It is usually treated with surgery, however, there are some other possible therapies.

### **HPV-related disease**

- HPV stands for **human papillomavirus**. There are at least 180 different types of HPV, and 40 of these affect the genitals. Some types of HPV cause genital warts. Chronic infection with high-risk HPV types can cause precancer and cancer of the head and neck and lower genital tract (including the vulva, vagina, cervix, and anus).
- The HPV virus is very common and is spread through skin-to-skin contact. Receiving the complete series of the HPV immunization (known as the Gardasil® vaccines) reduces your risk of getting an HPV-related disease to a very low risk level.

### **Genital warts (also called low-grade squamous intraepithelial lesions, or LSIL)**

#### **What are the symptoms?**

Warts do not turn into cancer, but the symptoms (bumps on the skin that can itch or bleed after getting rubbed or torn) can be very annoying, and you may decide you want treatment.

#### **What is the treatment?**

Treatments include topical medications, laser surgery, or surgery to remove the warts.



## **HPV-related precancerous lesions (also called high-grade squamous intraepithelial lesions, or HSIL)**

HSIL is related to chronic HPV infection, especially HPV types 16 and 18. It is abnormal tissue growth that can slowly develop into cancer if it is not treated. Known risk factors are a weakened immune system and cigarette smoking.

### **What are the symptoms?**

HSIL of the vulva may have no symptoms, or they may cause itching or burning. HSIL may look different for different people, but there is often a well-defined bump or area of thick skin that can be any color. We can diagnose HSIL using a special kind of exam technique using magnification, or a biopsy.

### **What is the treatment?**

Treatment depends on your goals and the size, number, and location of your lesions. The goal is to remove all of the abnormal tissue. Treatment includes topical medications, laser surgery, or surgery to remove the lesions.

## **Hidradenitis suppurativa**

- Hidradenitis suppurativa (HS) is a disease that most commonly affects parts of the body where your skin rubs against itself. This includes the armpits, under the breasts, the groin, the vulva, and the butt.
- HS is not caused by poor cleanliness. The cause is not fully understood, but it likely includes an abnormal immune system response to plugged hair follicles (the areas on your skin that hold your hair roots). This plugging is partly caused by abnormal shedding or clumping of the skin cells inside hair follicles.
- There are many factors that affect this disease, including genetics (something passed on to you from your parents), rubbing and pressure on the skin, smoking tobacco, weight, and hormones.

### **What are the symptoms?**

- HS causes chronic inflammation and bumps that look like pimples or boils. With more severe disease, it causes deep and painful areas of swelling that are often filled with fluid (called an **abscess**). When this abscess opens, pus or blood drains out.
- Repeated episodes of HS often leave scarring. In severe disease, there are draining skin tunnels (called **sinus tracks**). The chronic pain, draining fluid, and scarring can lead to depression and anxiety about close personal relationships.

### **What is the treatment?**

Treatment depends on the severity of the disease. It may include:

- Wearing looser clothing
- Stopping smoking
- Oral or topical antibiotics
- Oral contraceptive pills (birth control pills) or medications that block hormones that cause acne
- Steroid shots into inflamed skin
- Targeted therapy for the immune system (called biologics)
- Surgery

## **Vulvar pain and vulvodynia**

Vulvar pain can be so severe that it limits you from doing normal daily activities and makes sex painful. It can affect your entire vulva or only the vestibule (the opening to the vagina). By the time people with vulvar pain are seen at the Center for Vulvar Diseases, they may have had the pain for years. Like any chronic pain, this can lead to feeling depressed and hopeless. Our goals are to:

- Teach you ways to decrease pain and increase comfort that you can use right away
- Identify an underlying cause for your pain (if possible) and treat it
- Work with you long-term to treat the pain, knowing that it may take months before you feel better
- Give you mental and sexual health support from our sex therapists

### **What can cause vulvar pain?**

Chronic vulvar pain can be caused by:

- Skin irritation from something that you use repeatedly, such as hand or body soap, laundry soap, fabric softener, douche product, scented pads, or scented toilet paper
- Another vulvar skin condition
- Chronic yeast infections
- Herpes simplex virus (HSV) infection
- Nerve injury

Vulvar pain is not caused by poor cleanliness or anything you did wrong. It is also not contagious.

## How is vulvar pain treated?

Treatment of vulvar pain may include:

- Diagnosis and treatment of a vulvar disease
- Comfort measures (things you can do to decrease irritation, itching, and pain)
- Creams made by a specially trained pharmacist
- Oral medications
- Injections
- Surgery

We will work with you to choose the best treatment plan for you.

## What is vulvodynia?

**Vulvodynia** is vulvar pain that does not have a clear cause. It may be in a single part of the vulva, often around the vaginal opening, or may involve the entire vulva. The most common type of vulvodynia is pain at one site that happens only when there is pressure on that area. This may be caused by things like:

- Putting in a tampon
- Wearing tight pants
- Sexual activity that involves putting something in the vagina

## What is vaginismus?

**Vaginismus** is when your **pelvic floor muscles** - the muscles in your pelvis that stretch from your front pubic bone to your tailbone - tighten in response to the fear of pain. This tightening is not planned, and it happens without thinking. It can be compared to blinking if something is flying into your eye. These tightened muscles narrow or close the vagina, which can make it impossible or painful to have sex or insert a tampon.

There are successful treatments for vaginismus, such as:

- Pelvic floor physical therapy
- Dilator therapy (using a tampon-shaped device to relax and retrain your pelvic floor muscles)
- Topical medications
- Injections
- Surgery

We will work with you to choose the best treatment plan and, if needed, refer you to qualified physical therapists.

# Vulvar pain treatments and therapies

## Comfort measures

You may try the comfort measures listed below to relieve or prevent vulvar irritation, pain, and itching.

### Keep your skin dry

- Change out of wet clothes immediately after exercise or swimming.
- Get checked by a doctor and treated if you leak pee (you have urinary incontinence).
- Change pads or underwear as soon as they become wet.
- Do not wear panty hose, tights, or tight pants.
- Wear loose, airy clothing and keep your skin dry.
- Wear white (non-dyed) cotton underwear.
- Do not wear underwear in bed or while you're sleeping.

### Avoid skin irritants

Some household products have chemicals that can cause irritation to the vulva.

These include:

- Toilet tissue
- Laundry soap
- Fabric softener
- Dryer sheets
- Feminine hygiene products
- Diaper wipes
- Flushable wipes
- Panty liners
- Tampons
- Menstrual pads
- Incontinence pads

Follow these suggestions to reduce your contact to chemicals that may increase your itching and discomfort:

- Use chemical-free and fragrance-free laundry soaps or detergents.

- Rinse your clothing well. After washing your underwear, put it through at least 1 extra rinse cycle **with water only** to rinse out soap and chemicals.
- Do not use fabric softener or dryer sheets. If you feel you must use them, buy chemical-free and fragrance-free products. You may have to search online to find them.
- Wash any new underwear before wearing it.
- Use 100% cotton menstrual pads or tampons. You can find these at large retail stores (such as Walmart, Rite Aid, or CVS) or online.
- Make your own 100% white cotton wipes to use instead of toilet paper. Cut squares or rectangles from flannel you buy at the fabric store and wet them with water. Store the wipes in a plastic container.

### **Clean your body without irritation**

- Clean your vulva with water only.
  - Do not use soap, baby wipes, feminine hygiene wipes, douche, or bubble bath products.
  - You may use WaterWipes® if the main ingredient is listed as 99% water.
- Wash your other body areas with mild, fragrance-free soap such as Neutrogena Facial Cleansing Bar Fragrance Free®, Ivory®, or Dove®.
- Rinse your vulva often with water and pat dry. You can use a squirt bottle, hand-held shower nozzle, sitz bath, or bidet.
- Always gently pat your skin dry after washing or rinsing.

### **Try at-home treatments to soothe itching and irritation**

- Wrap a cool gel pack or bag of frozen peas in a thin towel and place it over your vulva. Do not leave it on for more than 20 minutes. Let your vulva come back to room temperature before reapplying a cool gel pack.
- Make a cold oatmeal paste compress following these steps:

1. Mix 2 tablespoons of ground or powdered oatmeal in 1 quart (4 cups) of water. You can grind your own oatmeal or use Aveeno® Colloidal Oatmeal in-bath treatment products.
  2. Refrigerate the paste and then spread it on a paper towel. Put the paste side of the towel against the itchy area of skin.
  3. Hold it there for 10-15 minutes. Then gently wash off the paste with water and pat the skin dry.
- Do not use over-the-counter (non-prescription) anti-itch creams that contain benzocaine, such as Vagisil®. They can cause severe irritation and inflammation, and make your itching worse.

## **Vaginal dilators**

### **What is a vaginal dilator?**

**Vaginal dilators** are smooth, solid objects that are shaped like a tampon. They are made in many different sizes. You can buy single dilators or kits that include a range of dilator sizes.

### **Why should I use a dilator?**

If you have vaginismus, you may use vaginal dilators to help relax and train your vaginal muscles to prevent unwanted muscle spasms. If you have a disease or condition that narrows your vaginal opening or shortens the length of your vagina, we may recommend you use dilators to prevent the vaginal walls from sticking together and narrowing or shortening your vagina.

### **What supplies do I need to use a dilator?**

- **Clean dilator:** You and your doctor will decide what size dilator to start with. Usually people start with one of the smallest sizes.
- **Hand mirror:** You may need a mirror at first to help you locate your vaginal opening.



- **Lubricant:** You can use a lubricant to make inserting the dilator easier and more comfortable. Read more about lubricants in a later section in this handout.

### **Where should I use my dilator?**

Find a private space where you will be comfortable and no one will disturb you. It is important for you to be in control and able to relax. Plan for 10-20 minutes of private time, 4-5 times a week, to use your dilator.

### **How do I use a dilator to treat vaginismus?**

1. Gather your supplies and get in a comfortable position (such as reclining or lying down). Put some lubricant on the tip of the dilator so it is ready to use.
2. Focus on breathing in and out. As you breathe out, relax your muscles.
  - Start by relaxing your neck muscles. Each time you breathe out, focus on relaxing other muscles moving down your body (shoulders, arms, back, legs). Finish with relaxing your pelvic muscles.
3. Slowly and gently start to push the dilator into the vagina.
  - At first, you may only be comfortable placing the dilator at the vaginal opening and not pushing it in any more. That is okay. The goal is to get used to something that causes discomfort until it no longer causes discomfort.
4. When you feel ready, try pushing the dilator into your vagina about 2 inches.
  - Check with your doctor about how deeply you need to insert the dilator. The pelvic muscles which tend to tense up are about 1 inch inside the vaginal opening. If you feel pain, stop and then gently pull the dilator back until there is no pain.

5. Leave the dilator in place for 10-20 minutes. You may have to hold the dilator in place during this time.
  - You may read, use cell phone apps, watch TV, meditate, or just think of things that make you feel happy during this time. Some people visualize (think about and try to picture) the dilator relaxing their vaginal muscles.
6. After 10-20 minutes, slowly remove the dilator.
  - After removing the dilator, clean it with regular soap and water. Dry it and put it away.
  - The dilator does not need to be sterilized. Do not use bleach or other cleaning products on it.

### **How do I use a dilator to prevent my vaginal walls from sticking together?**

You may need this if you have lichen planus or graft-versus-host disease (GVHD) affecting the vagina.

- We will help you decide which dilator size to use.
- You will gently insert the dilator into the full length of your vagina. We will tell you how often to do this.
- We may tell you to put a steroid cream on the dilator, so that you can use the dilator to put the cream into your vagina. You do not need to hold the dilator in the vagina. Simply inserting and removing it is enough. Some people choose to do this in the shower.

### **How do I know when to change the dilator size?**

- If your goal is to have vaginal sex, you may need to slowly increase the size of the dilator you use. When you can insert a dilator with very little or no discomfort or effort, it is time to use the next size up. To do this, start with the dilator you have been using. After a few minutes, switch to the larger dilator by following the same steps above.

- Don't lose hope if you feel like you are back at the beginning. It is expected for you to feel some resistance and discomfort each time you change to a larger size dilator.

### **When can I try having vaginal sex?**

You are ready to try vaginal sex when you do not have any muscle spasms or discomfort while using a dilator that is about the same size as your partner's erect penis or objects (toys) you want to use for sexual pleasure.

When you start having vaginal sex, it is important to:

- Talk with your partner about what to expect. You may want the penis or object to only touch your vaginal opening at first.
- Make sure you will have time and privacy so that you can relax and not feel rushed.
- Be in a position where you control how deeply the penis or object goes into your vagina.
- Think about using lubricant.



### **Where can I buy a dilator?**



We can provide you with a dilator at your visit. However, the cost is may be high if your insurance does not cover the dilator cost. Listed below are some less expensive options for dilator sets you can buy online.

- The list below is for your information and is not meant to endorse a specific product(s).
- **Circumference** is used to describe dilator sizes. Circumference means the length around the outside of a circular object. See the picture below for an example of how circumference relates to dilator size. It shows images of dilators with their circumference listed underneath.



6.25 inches	5.5 inches	5 inches	4 inches	3.25 inches	2.5 inches
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Dilator product information	QR code
<p><b>Dr. Laura Berman® dilator set</b></p> <ul style="list-style-type: none"> <li>• Go to <a href="http://DrLauraBerman.com">DrLauraBerman.com</a>. Click on “All Products” and select “Toys” from the dropdown menu, and then scroll until you see “CalExotics Dr. Laura Berman Dilator Set, 4 Locking Sizes Plus Sleeve.” Click on that page, and then you will need to click on a link to buy the product on Amazon.</li> <li>• The set includes a dilator made of plastic that fits 3 sleeves with circumferences from 2.75-4.75 inches. It has an optional vibrating function. Vibration may help to increase blood flow and lubrication.</li> <li>• You can also search the site for information about the dilator set and how to use it.</li> </ul>	
<p><b>Hope&amp;Her® dilator set</b></p> <ul style="list-style-type: none"> <li>• Go to <a href="http://HopeAndHer.com/collections/care-products/products/vaginal-insert-set">HopeAndHer.com/collections/care-products/products/vaginal-insert-set</a>.</li> <li>• This dilator set is made from medical grade hard plastic. The set includes 6 sizes with circumferences ranging from about 1.75-4.75 inches.</li> </ul>	

Dilator product information	QR code
<p><b>Intimate Rose® vaginal dilators</b></p> <ul style="list-style-type: none"> <li>• Go to <a href="https://www.intimaterose.com/collections/vaginal-dilators">IntimateRose.com/collections/vaginal-dilators</a>.</li> <li>• The full set includes 8 silicone dilators with circumferences from about 1.5-5 inches. You can buy the dilators individually or in a set of 4 in the small, medium, or large size range.</li> </ul>	
<p><b>Syracuse Medical vaginal dilators</b></p> <ul style="list-style-type: none"> <li>• Syracuse Medical does not have its own website. You will need to go to other supply sites such as <a href="https://www.cmtmedical.com/product/syracuse-medical-vaginal-dilators">CMTMedical.com/product/syracuse-medical-vaginal-dilators</a>.</li> <li>• These are made from medical grade (non-latex) plastic that has a very smooth texture. There are 7 sizes with circumferences from about 1.5-4.25 inches.</li> <li>• You can buy the different sizes individually, as a set of 4, or as a complete set.</li> </ul>	

**Lubricants**

In response to pleasure and sexual feelings or touch, the body produces its own vaginal lubricant. However, it is very common for couples to not spend the time needed for natural lubrication, and for people with vulvar disease or changes caused by menopause, natural self-lubrication may not be enough for comfort during sex. Lubricants increase comfort and pleasure during sexual activity. You can use lubricant on the vulva, around the vaginal opening, inside of the vagina, on a penis, or on a sex toy.

The U.S. Food and Drug Administration (FDA) does not do safety testing of lubricants, so it is important to educate yourself about the different types.

## **What are the different types of lubricants?**

### **Water-based lubricants**

Many lubricants are water-based. Many people who use them find that they increase pleasure and do not cause any problems. However, some water-based lubricants can cause irritation and damage vaginal tissue. Along with causing discomfort, this could increase the risk of getting a sexually transmitted infection (STI).

### **Silicone-based lubricants**

- Silicone lubricants last longer than water-based lubricants because they are not soaked up by the vaginal tissue. They may need to be rinsed off with water after sexual activity.
- In one study, the silicone-based lubricants that were tested did not damage skin cells from the lining inside the vagina or rectum. They were among the safest lubricants tested.

### **Oil-based lubricants**

While oils are not designed to be used as lubricants, some people use them to increase comfort. **Be aware that oil will break down latex condoms and dental dams.**

## **What are some lubricant ingredients to avoid?**

The ingredients listed below may irritate the vagina, so you may want to avoid lubricants that include them. Not everyone will be affected, but it is good to be aware of the ingredients in a lubricant before using it.

- Chlorhexidine gluconate
- Nonoxynol-9 or other spermicides
- Propylene glycol (this can also cause an allergic reaction, but it is not common)
- Perfumes or other scents

- Products that are labeled as warming, cooling, or tingling

### **Do lubricants cause yeast or bacterial infections?**

- There is no evidence that people who use vaginal lubricant products are more likely to get a yeast infection.
  - There is a false idea that glycerin, an ingredient in some lubricants, causes yeast infections. There is no scientific evidence for this. It is possible that very low concentrations (less than 5%) could support yeast growth, but glycerin is actually used in products to prevent bacteria and yeast growth.
- It is unclear whether lubricant use increases the risk of **bacterial vaginosis (BV)**, an imbalance of vaginal bacteria that can cause increased vaginal discharge, irritation, and a fishy smell.
  - One study showed that women who used petroleum jelly in the vagina within the past month were more likely to have BV. The same study showed that women who used oils were not more likely to have BV.

### **Vaginal moisturizers**

Vaginal moisturizers are designed to relieve or prevent daily dryness, irritation, and discomfort. They are used on a schedule, usually 3 times per week, rather than using them during sexual activity. There are many products available, such as Replens™ and Revaree®.

# Vulvar diseases and sexual health

## Why should I meet with a sex therapist?

- Sexual health is an important part of overall physical and emotional health. We believe that an important part of healing the whole person includes addressing issues related to sexuality.
- Pain and vulvar diseases can affect sexual feelings and sexual functioning for both you and your partner(s) in ways that other medical conditions do not. Vulvar problems can be much more emotionally intense than problems located in other parts of your body.
- Many vulvar diseases cause pain during sexual activity. It is normal to avoid from things that hurt, but over time this may create a pattern that makes it difficult to feel sexual desire and be sexually intimate (close) with others. Along with treating your vulvar disease, we can address and heal problems with sexual desire, functioning, or intimacy. We strongly encourage you and your partner(s) to meet with one of our sexual health counselors as part of your Vulvar Diseases Clinic visit.

## What is normal sexual health?

- Sexual health can be very different for different people. There is no “normal” - there is only what is important and comfortable for each individual and couple.
- Many people and their partners pause or give up on having a sexual relationship because of vulvar disease or pain. This may be due to changes in:
  - Sexual interest (also called **libido**)
  - The body’s response to sexual feelings or touch (also called **arousal**)
  - Lubrication



- Orgasm
- Your ability to enjoy vaginal sex
- Leaving these changes unaddressed can cause misunderstandings and difficult interactions between partners that may make the problem worse. Pain can also bring up body memories of past trauma or other painful times. Some people and their partners find creative ways to have sexual intimacy and feel satisfied. Others get a hopeless feeling that the negative changes are permanent. You may swing back and forth between both these feelings.
- With patience, time, and determination, these problems can be managed, corrected, and healed. We will help you get back to what is normal and satisfying for you. Below are some tips you can use to start the process. If you would like more support, a certified sex therapist is almost always present at our clinic, and they also provide counseling at the Center for Sexual Health. We can also recommend professionals in your area. In the resources section later on, there is information to help you find a certified sex therapist.

### **What are some tips to help with low libido?**

**Low libido** (low interest, or loss of interest, in sexual activity) is a very normal response to vulvar pain or disease, and it is the sexual complaint we hear most from our patients. Low libido is one way that the body teams up with the mind to protect you. If you had low libido or other sexual difficulties before your pain, these can combine to create a powerful pattern that prevents intimacy, even when you want to be closer to your partner. Along with getting support from a certified sex therapist or other counselor, here are some things you can do:

- **Listen to your body:** Avoid sexual activities that hurt. This may seem obvious, but some people accept pain because they do not want to disappoint their partner. However, most people are distressed when they

sense that their partner is not telling them about being in pain. They don't want to cause hurt or harm, and sex that causes pain is not enjoyable.

- **Communicate with your partner:** Your partner needs to know what hurts you, what feels good, and how best to approach sex with you. Sex is a team effort, and you can't play on a team without clear communication. Your partner may not be as understanding as you want them to be because they:
  - Do not understand your experience
  - Are frustrated
  - Feel helpless

Open communication, even if it feels scary to you, can help a great deal. Sometimes a couple needs to consult a counselor or therapist if it is difficult to start this conversation.

- **Have sex without penetration:** Try activities that do not involve putting anything in the vagina. The following things often feel good, and they can be exciting and satisfying:
  - Kissing
  - Fondling
  - Oral sex (using mouths)
  - Manual sex (using fingers)
  - Breast touching
  - Light touch
  - Massage
  - Sex using a vibrator

If you or your partner(s) don't like some of these ideas, talk about this together openly. With patience and clear communication, many couples have slowly become interested in and satisfied by other sexual activities.

- **Focus on sensual, as well as sexual, pleasure:** Sensual pleasure is pleasure to any of the physical senses: touch, taste, sight, sound, and smell. To feel sensual pleasure, you have to focus on what you are feeling, tasting, seeing, hearing, or smelling right now. It does not involve past fears or worries about the future.

- When sex becomes related to pain, sensual pleasure can also be lost. You can reintroduce sensuality with **non-demand** (meaning sex is not expected) activities. Cuddling, massage, a scented candle, listening to music, and a delicious treat are all sensual pleasures.
- Some couples stop touching each other after they have experienced the cycle of pain. Continuing pleasurable touch and affection is an important part of being intimate, even when sex is (at least for right now) not an option.
- **Remember that orgasm isn't everything:** Our culture tends to think of sex as trying to orgasm. Doing sexual and sensual play - where the goal is simply to experience the moment, have fun, and enjoy each other - has been freeing for many couples. They tell us that if anything can be considered positive about vulvar pain, it is how they have greatly expanded their idea of sex by a new focus on the pleasure of the moment and decreased focus on orgasm.

# Resources

## Websites for education and support

- **American Cancer Society:** For information about vulvar cancer, visit: [Cancer.org/cancer/vulvar-cancer.html](http://Cancer.org/cancer/vulvar-cancer.html)
- **Lichen Sclerosus Support Network:** LSSN is a not-for-profit organization whose mission is to empower people with lichen sclerosus by providing evidence-based education and support. Visit: [LSSupportNetwork.org](http://LSSupportNetwork.org)
- **DermNet NZ:** DermNet NZ was started in 1996 by a group of dermatologists from New Zealand. It has become a world-wide resource of skin disease information. Visit: [DermNetNZ.org](http://DermNetNZ.org)
- **Hope&Her:** Their stated goal is to be the place for the most up-to-date information and vaginismus support online. Visit: [HopeAndHer.com](http://HopeAndHer.com)
- **Hope for HS:** Hope for HS is a 100% volunteer, grassroots, patient and caregiver directed non-profit organization, supporting and advocating for hidradenitis suppurative (HS) patients since 2013. Visit: [HopeforHS.org](http://HopeforHS.org)
- **International Society for the Study of Vulvovaginal Disease (ISSVD):** The ISSVD includes about 500 gynecologists, dermatologists, pathologists, family practitioners, psychologists, sexual counselors, physical therapists, microbiologists, nurse practitioners, and others, all of whom are experts in some area of the study of vulvovaginal disease. Visit: [ISSVD.org/patient-education](http://ISSVD.org/patient-education)
- **National Psoriasis Foundation:** The National Psoriasis Foundation (NPF) is a non-profit organization with a mission to drive efforts to cure psoriatic disease and improve the lives of those affected. Visit: [Psoriasis.or/](http://Psoriasis.or/)
- **National Vulvodynia Association:** The mission of the National Vulvodynia Association (NVA), a non-profit created in 1994, is to help improve the health and quality of life for women with vulvodynia. Visit: [NVA.org](http://NVA.org)

## Websites for researching and buying products

- AH!YES (for lubricants and moisturizers): [AHYes.org/products](http://AHYes.org/products)
- Babeland (for lubricants and sex toys): [Babeland.com](http://Babeland.com)
- CheapLubes.com (for lubricants): [CheapLubes.com](http://CheapLubes.com)
- CMT (for dilators, lubricants, and moisturizers): [CMTMedical.com](http://CMTMedical.com)
- Dr. Laura Berman (for dilators): [DrLauraBerman.com](http://DrLauraBerman.com)
- Good Vibes (for lubricants and sex toys): [GoodVibes.com/s/](http://GoodVibes.com/s/)
- Hope & Her (for dilators): [HopeAndHer.com/collections/care-products](http://HopeAndHer.com/collections/care-products)
- Soul Source (for dilators and lubricants): [SoulSource.com/collections](http://SoulSource.com/collections)
- A Woman's Touch Sexuality Resource Center (for books, dilators, and lubricants): [SexualityResources.com](http://SexualityResources.com)

## Books

- *Completely Overcome Vaginismus: The Practical Approach to Pain-Free Intercourse, Book 1* by Mark and Lisa Carter
- *Completely Overcome Vaginismus: Personal Journal and Workbook, Book 2* by Mark and Lisa Carter
- *Sex Matters for Women, Second Edition: A Complete Guide to Taking Care of Your Sexual Self* by Sallie Foley, Sally A. Kope, and Dennis P. Sugrue
- *The Vulvodynia Survival Guide: How to Overcome Painful Vaginal Symptoms and Enjoy an Active Lifestyle* by Howard Glazer

## Resources for finding a counselor, therapist, or sex therapist

The certified sex therapist who you will meet with in the clinic can help you find a therapist. Here are some other resources you can use on your own:

- **American Association of Sexuality Educators, Counselors and Therapists (AASECT):** AASECT is a not-for-profit, interdisciplinary professional organization. Certification by AASECT as a sexuality educator, sexuality counselor, or sex therapist confirms that all the

requirements for training and experience have been met. Go to this site to search for a certified therapist near you: [AASECT.org/referral-directory](http://AASECT.org/referral-directory)

- **The Michigan Mental Health Networker:** This website provides a comprehensive listing of mental health agencies, psychotherapists, and self-help groups in Michigan. Visit: [MHWeb.org](http://MHWeb.org)
- **Michigan Department of Health & Human Services:** This site provides a map of the Community Mental Health Services Programs. Visit: [Michigan.gov/mdhhs/keep-mi-healthy/mentalhealth/mentalhealth/cmhsp/local-mental-health-services](http://Michigan.gov/mdhhs/keep-mi-healthy/mentalhealth/mentalhealth/cmhsp/local-mental-health-services)
- **University of Michigan Center for Sexual Health:** To schedule an appointment, call (734) 763-4963.

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Author: Diana Stetson, PA-C

Reviewer: Kathryn Welch, MD

Edited by: Brittany Batell, MPH MSW CHES®

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