

Vulvar Diseases

An Introduction to Caring for Yourself

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



MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

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What is the Center for Vulvar Diseases?

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

Clinic Providers

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

Doctors:

- **Medical Director- Kathryn Welch, MD**
Dr. Welch is an Assistant 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 of both the International Society for the Study of Vulvovaginal Diseases and the American Society for Colposcopy and Cervical Pathology.
- **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 Assistant 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.
- Ebony Parker-Featherstone, MD
Dr. Parker-Featherstone is an Assistant Professor in Family Medicine and Obstetrics and Gynecology, 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.
- Payton Schmidt, MD
Dr. Schmidt is an Assistant Professor in Obstetrics and Gynecology at the University of Michigan who specializes in Female Pelvic Medicine and Reconstructive Surgery. She completed medical school at Loyola University Chicago - Stritch School of Medicine and her Obstetrics and Gynecology residency, as well as her Female Pelvic Medicine and Reconstructive Surgery fellowship, at the University of Michigan. She is a member of the American College of Obstetricians and Gynecologists, American Urogynecologic Society, and Society of Gynecologic Surgeons.
- Abby Brown, CNM/FNP
Abby Brown is an experienced provider. She graduated from Vanderbilt University of Nursing with a dual degree in Nurse-Midwifery and Family Nurse Practitioner. She provides comprehensive obstetric and gynecologic care in addition to vulvar care.

Fellows:

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 chose to get advanced training in a specialty.

Residents:

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.

- Sara Zocher, LMSW
Sara also has experience working as a therapist in mental health, substance abuse, and domestic violence.

Nurses

Nurses are a valuable part of our team. They will teach you what you need to know about disease treatment and caring for yourself.

- Beth Hall, RN
Beth got her nursing degree from Eastern Michigan University. She is in charge of nursing care and follow-up for the Vulvar Diseases Clinic.

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 your concerns with them so that we can be aware of your needs.

Follow-up after your clinic visit

Your doctor will talk with you about whether a return visit is needed. If you were referred to the Center for Vulvar Diseases by a health care provider, we will send a letter to them that tells what we know about the cause of your illness and our plan for care. It is possible that the health care provider who

referred you will be able to continue your care. If not, you will be scheduled for a return visit. Sometimes, we will ask you to call or send a message instead of coming back for a visit.

What is the contact information for the clinic?

You may use the MyUofMHealth patient portal to send an email message or call (734) 763-6295 between 8am-5pm Monday through Friday. If you want to reschedule a visit, it is better to call than to send a message.

All messages or calls are first reviewed by a nurse who will decide what best meets your need. This could be:

- giving you 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

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 one 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 medicine or other treatment plan.
- **Tell us your symptoms are worse, or 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 medicine 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 with the health care 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 medicine. Plan for 3 days to get your

prescription refilled. We do not check messages sent on a weekend until the following Monday. Make sure you give us the following:

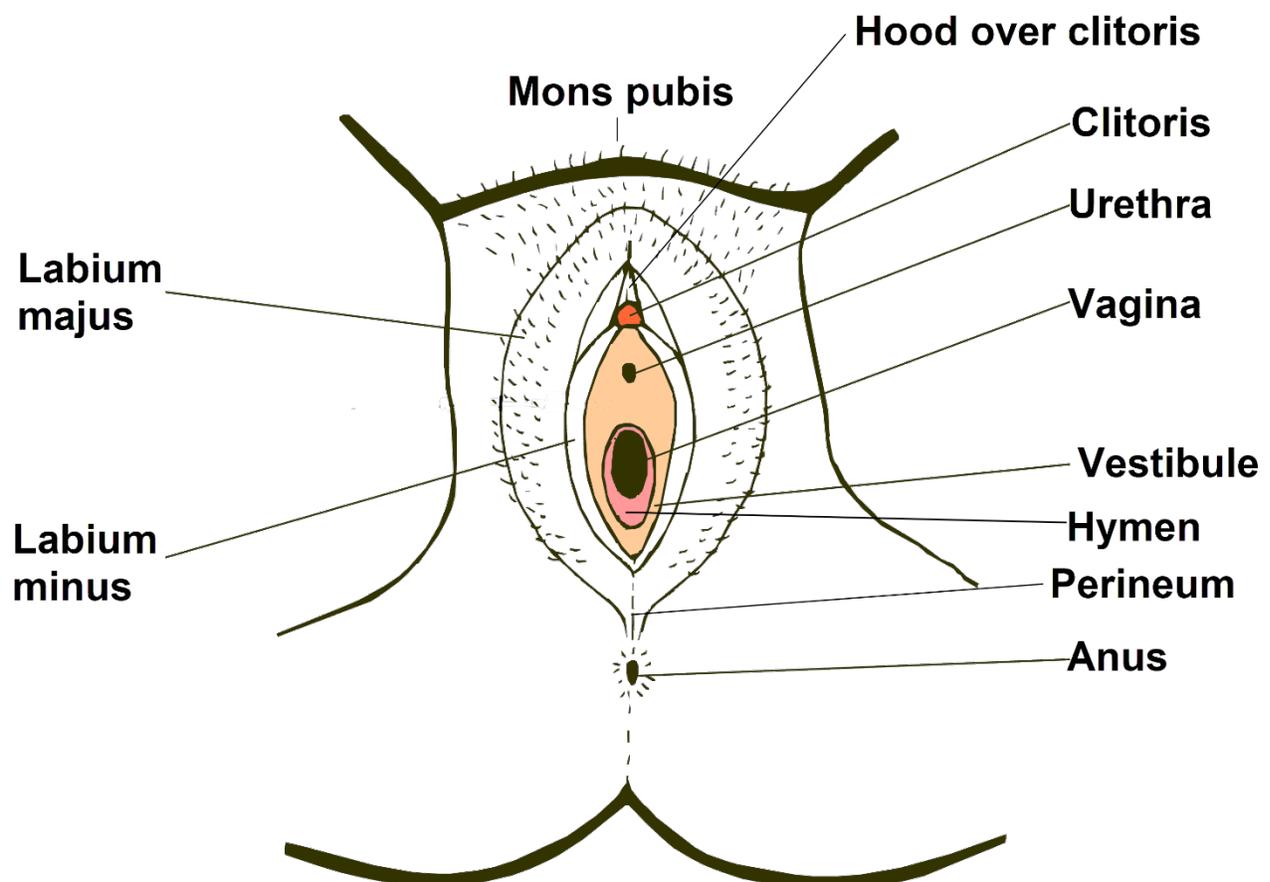
- medicine name and dose
- pharmacy name, phone number, and fax number

What is the vulva?

The **vulva** is the part of the body that includes the external female genital parts that are located in between the lower abdomen and the and anus (the opening that stool comes out of). See **figure 1** below. These genital parts include: the mound of fatty tissue above the pubic bones (mons pubis), the large outer lips (labia majora), small inner lips (labia minora), clitoris, the opening that urine comes out of (urethra), and the opening to the vagina (vestibule).

Figure 1

Image showing the anatomy of the vulva.



Miguelferig, CC0, via Wikimedia Commons

How do I inspect my vulva for disease?

It is important to find vulvar disease at an early stage when it can best be treated. Get evaluated for symptoms such as itching or bleeding and inspect your vulva to find changes that need evaluation. Some changes can be a sign of cancer and should not be ignored. Just like other parts of your body, you should know what your vulva looks like so you can identify a new change that should be evaluated.

Every woman's vulva has the same parts, but there is a wide variety in how they look. For example, the **labia minora** (inner lips) may be longer than the **labia majora** (outer lips) for some women, and shorter for others. The two sides of the labia minora may look different. This is all normal. The way your vulva looks is normal for you. Do a self-exam using a mirror once a month or when you have new symptoms that are concerning. See **figure 1** on page 8 to help orient you as you look.

What are the steps for doing self-exam?

1. Wash your hands thoroughly.
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: lie or sit with your back resting on pillows, or squat or kneel.
4. If you have not looked at your vulva before, it may look different than what you expect. The labia minora (inner lips) may be shorter or longer than the labia majora (outer lips). One side may be longer than the other. 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.
5. Inspect the mons pubis, outside of the labia majora, and perineum.
6. Gently separate the labia majora and inspect the inside of the lips and in between the labia majora and minora.

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

When do I need evaluation?

Schedule a visit if you find:

- Skin changes that are:
 - Raised
 - Rough
 - White
 - Thickened
 - Red
 - Raw
- Blisters (fluid filled bumps)
- Moles with:
 - One half that is unlike the other half
 - Borders that are irregular, scalloped, or poorly defined
 - Different colors or thicknesses
 - Size bigger than a pencil eraser.

Vulvar Diseases

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

Definitions of medical terms

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, examination often includes a **biopsy** (removing a small piece of skin) for laboratory diagnosis. We will give you a shot of numbing medicine before the skin is removed.

Inflammation

The body's response to injury, infection, or disease. Heat, swelling, and pain are signs of inflammation.

Chronic

Lasting a long time.

Immune system

Our body's way to recognize and fight:

- Germs that cause disease
- Harmful substances
- Abnormal changes in your body such as cancer

Autoimmune disease

A disorder that is caused by your immune system attacking part of your own body.

Oral medication

Something that is swallowed such as a tablet or capsule.

Topical medication

Something that is applied to the skin, like a cream or ointment.

Itch-Scratch-Itch Cycle

What are the symptoms?

Vulvar itching can be caused by many different diseases or skin irritants. Scratching and rubbing may bring relief for a moment, but they irritate the skin which in turn causes more itching. This itch-scratch-itch 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. 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.

These are some of the causes of vulvar itching:

Diseases:

- Eczema
- Yeast or fungal infection
- Psoriasis
- Lichen sclerosus
- Anxiety
- Depression

Skin irritants:

- Scented soap, laundry detergent or toilet tissue
- Scented condom, pad, or tampon
- Skin medicine or cream
- Urine
- Sweat
- Wet bathing suit
- Contraceptive jelly or spermicide
- Vaginal lubricant
- Frequent washing with soap
- Frequent cleaning with baby wipes

Lichen Simplex Chronicus

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 medicine:

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

Chronic or recurrent yeast infection

What are the symptoms?

Common symptoms from yeast infection include itching, burning, swelling, and a thick white discharge with cottage-cheese-like clumps. Women who think they have repeated yeast infections may actually have a different disease.

What is the treatment?

We will look for all possible causes of your symptoms and get a yeast culture 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.

Treatments include

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

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

Lichen Sclerosus

What are the symptoms?

Lichen sclerosus is a skin condition that causes itching, discomfort, and pain. Sexual activity is often very painful. It may involve the entire vulva, from the hood of the clitoris to around the anus. The affected skin is:

- Fragile and tears easily
- Often has a white color
- Often has a thin, shiny, crinkled appearance.

Untreated lichen sclerosus can cause scarring and changes in the appearance of the vulva.

Chronic inflammation from lichen sclerosus can cause abnormal growth called **differentiated vulvar intraepithelial neoplasia (dVIN)**. If untreated, dVIN can progress to vulvar cancer. Overall, 3 out of 1,000 women will develop vulvar cancer during their lifetime. For women with lichen sclerosus, the likelihood is about 40 out of 1,000. Treatment with topical steroids lowers the risk of getting dVIN and cancer.

What is the treatment?

Treating the skin with steroid ointments usually relieves the itching. It is a chronic disease and treatment must be continued for a long time to keep symptoms from coming back, stop chronic inflammation, and prevent scarring. There are other treatments if this does not work.

Lichen Planus

What are the symptoms?

When it affects the vulva and vagina, lichen planus is an autoimmune disease that causes:

- Itching
- Burning
- Pain
- Inflammation

Lichen planus is a type of lichen planus that affects the moist skin that protects the inner vulva, vagina, and inside of the mouth. It causes red, swollen tissue and open sores.

If untreated, it can cause scarring that narrows or closes the vagina.

Many women 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 well-defined patches that may be glossy red or gray colored. White or silver scales may be present or may have been rubbed off. Most women 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. In addition to the changed appearance of the skin, it may cause itching or painful 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 Disease

What are the symptoms?

Paget disease causes slightly raised, red patches of skin with itching or burning pain. The cause is not known. Up to 3 in 10 women with Paget disease of the vulva have invasive cancer in the vulva. However, it may occur in other organs such as the urethra, rectum, or bladder. We will discuss what kind of evaluation you need at your appointment.

What is the treatment?

It is usually treated with surgery.

HPV-related disease

HPV stands for human papillomavirus. There are at least 180 different types of HPV, 40 of these affect the genitals. Some types of HPV cause genital warts.

Chronic infection with high-risk types can cause cancer of the:

- Vulva
- Cervix
- Mouth
- Throat

The virus is spread through skin-to-skin contact. Condoms reduce the risk, but do not prevent all skin-to-skin contact. If you got the complete series of HPV

immunization shots (Gardasil) your risk of getting an HPV-related disease is very low.

HPV and genital warts (condyloma acuminata)

What are the symptoms?

HPV types 6 and 11 are the most common cause of genital warts. Here is what you need to know about warts:

- They usually first appear as a small bump on the skin that often grows larger.
- A single wart may be surrounded by smaller warts. Sometimes they grow to form a large cluster of warts that has the shape of a cauliflower.
- If you have a disease or take medications that weaken the immune system, your warts can grow very large.
- Warts often return after treatment.
- Warts do not turn into cancer but symptoms can be very bothersome.

What is the treatment?

The most common treatments involve applying a medicine to the wart. This can be done by a health care provider at the clinic or you may be prescribed a treatment you can do at home. If this does not work, there are other options including laser therapy or surgery.

HPV and High-Grade Squamous Intraepithelial Lesion (HSIL)

HSIL, also called usual-type vulvar intraepithelial neoplasia (uVIN) is associated with chronic HPV infection, especially types 16 and 18. It is abnormal tissue growth that can progress to cancer if it is not treated. Fortunately, this process usually takes years so there is time for diagnosis and treatment if you get regular exams and don't ignore symptoms. Cigarette smokers have a higher risk of getting HSIL than non-smokers. The average age at diagnosis is between age 40 and 50.

What are the symptoms?

HSIL of the vulva may be present without any symptoms or may cause itching or burning. Symptoms often are focused in one spot or area of the vulva. The appearance varies, but there is often a well-defined bump or area of thick skin that can be any color. A diagnosis is made using a special kind of exam technique using magnification, or a biopsy.

What is the treatment?

Treatment depends on how much HSIL has progressed size, and the location of the HSIL. The goal is to remove all of the abnormal tissue. This is usually done with surgical removal or laser removal under anesthesia. Laser removal uses light to heat and destroy HSIL. Sometimes, a topical antiviral medication is used. It is important to get routine check-ups after treatment to find and treat reoccurring HISL early.

Hidradenitis suppurativa

Hidradenitis suppurativa (HS) is a disease that most commonly affects parts of the body where skin rubs against itself, this includes:

- Armpits
- Under the breasts
- Groin
- Vulva
- Buttocks

What are the symptoms?

It causes chronic inflammation and recurrent bumps that look like pimples or boils. With more severe disease, it causes deep and painful areas of swelling that are often filled with pus (called an abscess). When this opens, pus or blood drains out. Repeated episodes 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 intimate relationships.

HS is not caused by poor hygiene. The cause is not fully understood, but it likely includes an abnormal immune system response to plugged hair follicles. Plugging is in part caused by abnormal shedding or clumping of the skin cells inside hair follicles.

There are many factors that affect the disease:

- Genetics (something inherited from biological parents)
- Rubbing and pressure on skin
- Smoking tobacco
- Overweight
- Hormones

What is the treatment?

Treatment depends on the severity of the disease. It includes

- Loose clothing
- Stopping smoking
- Oral or topical antibiotic
- Oral contraceptive pill (birth control) or medicine that blocks hormones that cause acne
- Steroid shot into inflamed skin
- Targeted therapy for the immune system
- Surgery

Vulvar pain and vulvodynia

Vulvar pain can be so severe that it limits doing normal daily activities and makes sex painful. It can affect the entire vulva or only the vestibule (opening to the vagina). By the time women 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 down 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 (if possible) and treat it.
- Work with you long term to treat the pain, knowing that it may take months before you feel better (most of the time).
- Give you mental and sexual health support from our sex therapists.

What can cause vulvar pain?

Chronic vulvar pain can be caused by:

- Skin injury from something that is used repeatedly such as:
 - soap
 - laundry soap
 - fabric softener
 - douche
 - scented pad
 - scented toilet paper
- Underlying vulvar skin condition
- Chronic yeast infection
- Herpes simplex virus (HSV) infection
- Nerve injury

Vulvar pain is not:

- Caused by poor hygiene
- Contagious
- Caused by something you did wrong

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 pressure is applied, for example:

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

Treatment of vulvar pain includes:

- Diagnosis and treatment of an underlying disease
- Comfort measures
- Creams made by a specially trained pharmacist
- Oral medicines
- Injections
- Surgery

We will work with you to choose the best treatment plan

Vaginismus (vaj-i-nis-mus)

Vaginismus is when the pelvic floor muscles tighten as a response to fear of pain. This is not planned and it happens without thinking. It can be compared to blinking if something is flying into your eye. The tightened muscles narrow or close the vagina. This can make it impossible or painful to have sex or insert a tampon.

Pelvic floor muscles are located in your pelvis and stretch like a hammock from the pubic bone (at the front) to the coccyx or tailbone (at the back) and from side to side.

Fortunately, there are successful treatments such as:

- Pelvic floor physical therapy

- Dilator therapy (a tampon-shaped device used 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.

Comfort measures for all vulvar diseases: what you can do to relieve or prevent vulvar irritation, pain, and itching

#1: Keep your skin dry:

- Change out of wet clothes immediately after exercise or swimming.
- Get evaluated and treated if you leak urine (urinary incontinence).
- Change pads or underwear as soon as they become wet.
- Do not wear panty hose, tights or tight pants.
- Wear loose clothing that allows air to circulate and keep skin dry.
- Wear white cotton underwear and do not wear underwear at night.

#2: Avoid skin irritants

Some household products have chemicals that can cause irritation to the vulva, these include:

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

Follow these suggestions to reduce exposure to chemicals that may increase your itching and discomfort.

- Use chemical-free and fragrance-free laundry soaps or detergents.
- Rinse clothing thoroughly. After washing underwear, put it through at least one 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 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, but you may have to shop 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.

#3: Clean without irritation:

- Do not use:
 - Soap
 - Baby wipes
 - Feminine hygiene wipes
 - Douche
 - Bubble bath
- Clean the vulva with water only (WaterWipes® are okay if the primary ingredient is listed as 99% water)
- Wash other body areas with mild, fragrance-free soap such as Neutrogena Facial Cleansing Bar Fragrance Free®, Ivory® and Dove®.
- Rinse the vulva with water frequently and pat dry. You can use a squirt bottle, hand-held shower nozzle, sitz bath, or bidet.
- Always gently pat the skin dry after washing or rinsing.

#4 Try at home treatments for irritation:

- Wrap a cool gel pack or bag of frozen peas in a thin towel and drape it over the vulva. Do not leave on for more than 20 minutes. Let the vulva come back to room temperature before reapplying a cool gel pack.
- Make a cold oatmeal paste compress:
 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 to 15 minutes. Then gently wash off 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, inflammation, and worsen itching.

Other therapies for vaginal diseases:

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 purchase individual dilators or kits that include a range of sizes.

Why should I use a dilator?

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

What supplies do I need to use a dilator?

Supplies:

- Clean dilator

You and your doctor will decide what size dilator to start with. Usually women start with one of the smallest sizes.

- Hand mirror

You may need a mirror at first to help you locate the vaginal opening. For help, see the labeled drawing in the ‘What is the vulva section?’ on page 8.

- Lubricant

You can use a lubricant to make inserting the dilator easier and more comfortable. For more information, go to the Vaginal Lubricants section on page 29.

Privacy:

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 to 20 minutes of private time 4 to 5 times a week.

How do I use a dilator to treat vaginismus?

1. Gather supplies and get in a comfortable position. Apply some lubricant to the tip of the dilator so it is ready to use.
2. Focus on just breathing in and out. As you breathe out, relax your muscles. Start with your neck muscles so that your head feels heavy and you need a pillow or cushion to support it. With each breathe out, focus on relaxing muscles as you work down your body. Finish with relaxing the pelvic muscles.
3. Slowly and gently begin to push the dilator into the vagina. At first, you may only be comfortable placing the dilator at the vaginal opening and doing no more. That is okay. The goal is to get used to something that causes discomfort until it no longer causes discomfort. When you feel ready, try

pushing the dilator in about 2 inches. You do not need to completely insert the dilator. The pelvic muscles which tend to tense up are about one inch inside the vaginal opening. The goal of dilator use is to retrain these muscles so that they stay relaxed. If you feel pain, stop and then gently pull the dilator back until there is no pain.

4. Leave the dilator in place for 10 to 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. Some women visualize the dilator relaxing their vaginal muscles.
5. After removing the dilator, clean it with hand 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 the vaginal walls from sticking together?

This may be needed if you have lichen planus or graft versus host disease affecting the vagina.

- We will help you decide which dilator size to use.
- You will gently insert the dilator into the full length of the 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 in the vagina. You do not need to hold the dilator in the vagina. Simply inserting and removing it is enough. Some women 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 gradually 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 outlined above. Do not get discouraged 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.

When can I try vaginal sex?

You are ready when you do not have any muscle spasm 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:

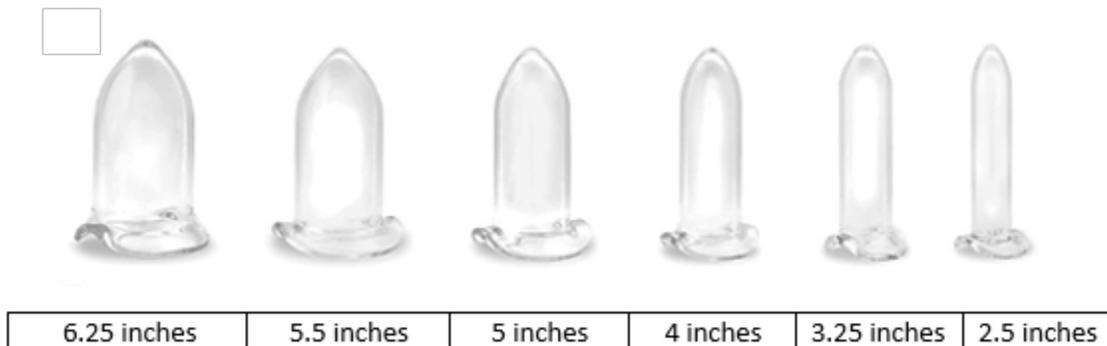
- Talk with your partner about what to expect. You may want the penis or object to only touch the vaginal opening at first.
- Make sure you will have time and privacy so that you can relax and not feel rushed.
- Be in a position where you control the depth of penetration.
- Be open to using vaginal lubricant.

How do I purchase dilators?

We can provide you with a dilator at your visit. However, the cost is relatively high if your insurance does not cover dilator cost. These are some less expensive options for buying dilator sets online. The list below is for your information and is not meant to endorse a specific product(s).

Note: Circumference is used to describe dilator sizes. **Circumference** means the length around the outside of a circular object. See **figure 2** below. for an example of how circumference relates to dilator size. It shows images of dilators with their circumference listed underneath.

Figure 2



Source: Vaginismus Treatment: Clinical Trials Follow Up 241 Patients Pacik P.T., Geletta S. (2017) Sexual Medicine, 5 (2) , pp. e114-e123.

Dr. Laura Berman Intimate Basics Dilator Set

- Go to <https://drlauraberman.com/> and click “shop” then scroll down until you see the dilator set. You will need to purchase it on Amazon.
- The set includes a dilator made of supple silicone that fits 3 sleeves with circumferences from 2 and $\frac{3}{4}$ inches to 4 and $\frac{3}{4}$ inches. It has an optional vibrating function. Vibration helps to increase blood flow and lubrication.
- You can also search the site for information about the dilator set and how to use it.

Hope & Her

- Go to <https://hopeandher.com/products/vaginal-dilator-set>
- These are made from medical grade hard plastic. The set includes 6 sizes with circumference ranging from about 1 and $\frac{3}{4}$ inches to about 4 and $\frac{3}{4}$ inches.

Intimate Rose Vaginal Dilators

- Go to <https://www.intimaterose.com/collections/vaginal-dilators>.
- Full set includes 8 silicone dilators with circumference from about 1 and $\frac{1}{2}$ inches to about 5 inches. You can buy the dilators individually or in a set of 4 in the small, medium, or large size range.

Syracuse Medical Vaginal Dilators

- Syracuse Medical does not have its own web site. You will need to go to other sites such as:
<https://bodyreliefdepot.com>
<https://www.cmtmedical.com/product-category/pelvic-pain/dilators/>.
- These are made from medical grade (non-latex) rigid plastic that has a very smooth texture. There are 7 sizes with circumference from about 1 and ½ inches to about 4 and ¼ inches.
- You can buy the different sizes individually, as a set of 4, or as a complete set.

Vaginal lubricants

In response to enjoyable sensual and sexual stimulation, the female body produces its own vaginal lubricant. However, it is very common for couples to not spend the time needed for natural lubrication. And, for women with vulvar disease or changes caused by menopause, natural self-lubrication may not be enough for comfort. This can happen even when couples take enough time and attention for arousal. Vaginal lubricant products increase comfort and pleasure during sexual activity. Lubricants can be applied to the vulva, around the vaginal opening, inside of the vagina, on the 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. The information in this section will help you be a careful consumer.

Water-based lubricants

Most lubricants are water-based. Many women who use them find that they increase pleasure and do not cause any problems. However, scientific research has shown that some water-based lubricants can cause irritation and damage

vaginal tissue. In addition to causing discomfort, this could increase the risk of getting a sexually transmitted infection.

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.

In one study, both of 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 marketed to be lubricants, many women use them to increase comfort. Be aware that **latex condoms and dental dams rapidly lose strength when exposed to oil-based lubricants.**

Irritants that may be present in lubricants

The ingredients listed below are vaginal irritants. 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 (can also cause an allergic reaction but it is not common)
- Perfumes or other scents
- Products that are labelled as warming, cooling, or tingling

Do lubricants cause infections?

Candida (yeast) infection

There is no evidence that women who use vaginal lubricant products are more likely to get a yeast infection. There is a misconception 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.

Bacterial vaginosis (BV)

BV is an imbalance of vaginal bacteria that can cause increased discharge, irritation, and a fishy odor.

- Petroleum jelly

One study showed that women who used petroleum jelly in the vagina within the past month were more likely to have BV.

- Oils

The same study showed that women who used oils (types not known) were **not** more likely to have BV.

- Lubricant products

It is unclear whether lubricant use increases the risk of BV. Results from 3 studies were not consistent. The 2 studies that looked at any use in the past 1 to 3 months did not find any increased risk for BV. In the other study, women collected a sample from their vagina for testing every 3 days. Those who used a lubricant the day before testing were 12 times more likely to have BV than women who did not use a lubricant product. However, many women with a test showing BV did not have any symptoms and often went back to normal on their own.

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 with sexual activity. There are many products available. Some are listed below. You will be able to find the moisturizer that works best for you.

- Replens™
- 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 diseases of the vulva can affect sexual feelings and sexual functioning for both you and your partner 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 move away from things that hurt, but a pattern can be created over time that makes it difficult to feel sexual desire and resume sexual intimacy. We want you to know that in addition to treating the vulvar disease, we can address and heal problems with sexual desire, functioning, or intimacy.

Therefore, you and your partner are strongly encouraged 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 women and their partners temporarily stop or give up on having a sexual relationship because of vulvar disease or pain. This may be due to changes in:

- Sexual interest (libido)
- Arousal
- Lubrication
- Orgasm

- Ability to enjoy vaginal penetration

Leaving these changes unaddressed can cause misunderstandings and negative interactions between partners that worsen the problem. Pain can also bring up body memories of past trauma or other painful times.

Some women 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 addressed, corrected and healed. We will help you get back to what is normal and satisfying for you. Tips you can use to start the process are described below. 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 recommend professionals in your area. In the resources section on page 35 there is information to help you find a certified sex therapist.

Low libido

Low libido (low interest or loss of interest in sexual activity) is a very normal response to vulvar pain or disease and 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 low libido or other sexual difficulties were present even before the pain, these can combine to create a powerful pattern that prevents intimacy even when you want to be closer to your partner. In addition to 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 women

accept pain because they do not want to deprive their partner of sexual satisfaction. However, most people are distressed when they sense that their partner is not being straightforward 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 scary, 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 often feel good and can be stimulating and satisfying:

- Kissing
- Fondling
- Oral sex
- Manual sex
- Breast touching
- Light caress
- Massage
- Sex using a vibrator

If you or your partner object to some of these ideas, discuss this together frankly. With patience and clear communication, many couples have gradually become interested in and satisfied by alternative 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 associated with 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 temporarily) not an option.

- **Orgasm isn't everything**

Our culture tends to reduce sex to the pursuit of orgasm. Doing sexual and sensual play where the goal is simply to experience the moment, have fun, and enjoy each other has been liberating for many couples. They tell us that if anything can be considered positive about vulvar pain, it is how they have greatly expanded their definition 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 regarding vulvar cancer visit:

<https://www.cancer.org/cancer/vulvar-cancer.html>

- The Association for Lichen Sclerosus & Vulval Health

The association's aim is to offer responsible and medically sourced

information and support for people with lichen sclerosus.

Visit: <http://lichensclerosus.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: <https://dermnetnz.org/>

- Hope & Her

Their stated goal is to be the place for the most up-to-date information and vaginismus support online.

Visit: <https://hopeandher.com/>

- Hope for HS

Hope for HS is a 100% volunteer, grass-roots, patient and caregiver directed non-profit organization, supporting and advocating for HS patients since 2013.

Visit: <https://hopeforhs.org/>

- International Society for the Study of Vulvovaginal Disease (ISSVD)

The ISSVD consists of approximately 500 gynecologists, dermatologists, pathologists, family practitioners, psychologists, sexual counselors, physical therapists, microbiologists, nurse practitioners, and others, all of whom have distinguished themselves in some area of the study of vulvovaginal disease.

Visit: <https://www.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: <https://www.psoriasis.org/>

- 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: <https://www.nva.org/>

- UpToDate® Beyond the Basics
Beyond the Basics articles provide more in depth and detailed information. They are written for patients who are comfortable with some technical medical terms.

Visit: <https://www.uptodate.com/contents/table-of-contents/patient-information/beyond-the-basics>

Websites for researching and purchasing products

- AH!YES (lubricants and moisturizers with pH matching that of the vagina)
<https://www.ahyes.org/products/>
- Babeland (lubricants, sexual aids)
<https://www.babeland.com/>
- Body Relief Depot (dilators)
<https://bodyreliefdepot.com/brd/>
- CheapLubes.com (lubricants)
<https://www.cheaplubes.com/>
- CMT (dilators, lubricants, moisturizers)
<https://www.cmtmedical.com/>
- Dr Laura Berman (dilators)
<https://drlauraberman.com/>
- good vibrations (lubricants, sexual aids)
<https://www.goodvibes.com/s/>
- Hope & Her (dilators)
<https://hopeandher.com/products/vaginal-dilator-set>
- Soul Source™ (dilators, lubricants)
<https://www.soulsource.com/pages/products>
- A Woman's Touch (books, dilators, lubricants)
<https://sexualityresources.com/>

Books

- Completely Overcome Vaginismus (Book 1): The Practical Approach to Pain-Free Intercourse, by Mark and Lisa Carter
- Completely Overcome Vaginismus (Book 2): Personal Journal and Workbook, 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 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 with whom you meet in the clinic can help you find a therapist. In addition, here are some resources you can use on your own:

- American Association of Sexuality Educators, Counselors and Therapists
The 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:
<https://www.aasect.org/referral-directory>.
- The Michigan Mental Health Networker
Provides a comprehensive listing of mental health agencies, psychotherapists and self-help groups in Michigan.
<http://www.mhweb.org/>.
- Michigan Department of Health & Human Services
This site provides a map of the Community Mental Health Services Programs
https://www.michigan.gov/mdhhs/0,5885,7-339-71550_2941_4868_4899-178824--,00.html
- University of Michigan Center for Sexual Health
To schedule an appointment call (734) 763-4963.

Disclaimer: This document contains information and/or instructional materials developed by the Michigan Medicine for the typical patient with your condition. It may include links to online content that was not created by Michigan Medicine and for which Michigan Medicine does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition or your treatment plan.

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