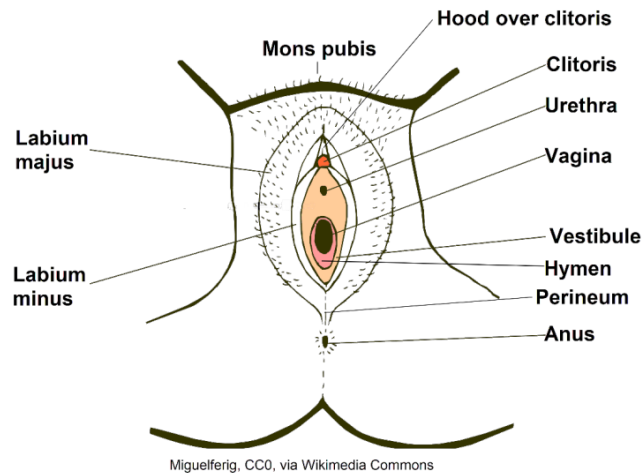


# Vulvodynia

## What is vulvodynia?

**Vulvodynia** is pain that is present anywhere in the vulva for more than 3 months without a known cause.

- The **vulva** is the part of the body that includes all the external (outside the body) genital parts. It covers the area from where pubic hair grows (the **mons pubis**) to the opening that stool comes out of (the **anus**). The vulva includes the large outer lips of skin (**labia majora**), small inner lips of skin (**labia minora**), the clitoris, the opening that urine comes out of (**urethra**), and the opening to the vagina. The **vestibule** is the area between the inner lips and the vaginal opening.



At some time in their lives, many people will have vulvar pain with a clear cause (for example, pain from a tear during childbirth or pain caused by a yeast infection). This pain usually goes away after treatment or after they have time to heal. Vulvodynia is different because the pain does not go away with time and there is no clear cause for the pain.

## What are possible causes of vulvodynia?

Below are some factors that are possibly related to vulvodynia, but there is limited research on whether these factors cause vulvodynia. It is possible that vulvodynia is related to, or made worse by, more than one of these factors.

### Genetics

**Genetics** are family traits passed from parent to child. If a family member has a history of vulvodynia, it could be more likely for another family member to be affected.

### Hormones

**Hormones** are chemicals in your body that send messages that help your body to function (work properly). For some people, the hormones in birth control pills can increase their risk of getting vulvodynia.

### Musculoskeletal (muscle system) factors

**Pelvic floor muscles** (the muscles around the bottom of your pelvis that support your bladder, bowels, and uterus) that are weak, tight, or not stable may cause of vulvar pain. Pain can also cause pelvic muscle tightness (**spasms**), as your body tries to protect itself from pain.

### Neurological factors

Neurological factors relate to your **nervous system**, which includes your brain, spinal cord, and nerves.

- Your brain can change what would normally feel like mild pressure or irritation in an area of your body (like your vulva) into a feeling of severe pain.
- When some pieces of vulvar skin were removed from people with vulvodynia (called taking a **biopsy**), they found an increase in the number of nerve endings that feel pain. People with vulvodynia have more nerve

endings in the painful area of vulvar skin than people who don't have vulvodynia.

### **Other pain conditions**

People with vulvodynia often have other chronic pain conditions without a known cause, including:

- Fibromyalgia
- Irritable bowel syndrome
- Orofacial (mouth, jaw, and face) pain
- Painful bladder syndrome (called interstitial cystitis)

### **Psychosocial factors**

- Vulvodynia is not caused by anxiety, and the pain of vulvodynia is real. However, people with vulvodynia are more likely to have anxiety, depression, and post-traumatic stress disorder (PTSD, which occurs after a stressful event) than people without these issues. These disorders may be both a reason for vulvodynia and a result of dealing with **chronic** (long-term) pain.
- Your feelings about pain are formed by your family, community, and your own personality. This can affect how much pain you feel, how bad it feels, and its impact on your daily life.
- The feelings of other people in your life, especially the feelings of a current or possible future sexual partner, can also have a strong impact on how vulvodynia affects you.

### **What are the symptoms of vulvodynia?**

Symptoms of vulvodynia can be very different for different people. To best understand your pain so we know how to treat it, we need to know:

- What does it feel like?

- Vulvodynia pain is often described as burning, but it may also feel sharp, pressure, aching, or something else.
- Where is it located?
  - Your pain may include the entire vulva (**generalized vulvodynia**) or it may only be in a smaller specific area (**localized vulvodynia**).
- What seems to cause your pain or make it worse?
  - **Spontaneous pain** is pain that can happen at any time for no clear reason.
  - **Provoked pain** is a pain that happens only when there is pressure on the vulva (such as from wearing tight clothes, using a tampon, or sexual activity). We will want to know if you've always had pain when doing these things, or if your pain started later in your life.
- How long does the pain last?
  - You may have pain all the time or, if you have provoked pain, your pain may stop soon after you stop the activity that's causing pressure.
  - Over time, your pain may stay the same or it may sometimes go away or get less severe without any clear reason.

### **How is vulvodynia diagnosed?**

Vulvodynia is a **diagnosis of exclusion**, meaning that we first have to rule out other causes of vulvar pain.

- We will do a pelvic exam, and we may use a small swab or Q-tip® to collect a sample to rule out a yeast infection or bacterial infection. We will also use the soft side of a Q-tip® and touch your vulva in different areas to figure out where you feel the pain and how bad your pain is.
- If there is anything that looks abnormal, we may need to **biopsy** (remove) a small piece of skin to send to the laboratory to check for other diseases. We will give you a numbing injection (shot) that will help you not feel anything in that area before we remove the skin.

- If we don't find any other infection or disease, then the diagnosis is vulvodynia.

### **How is vulvodynia treated?**

Vulvodynia is hard to treat, and it is common to need long-term treatment that can last weeks, months, or even years. The goal of treatment is to make your pain symptoms go away, or to at least reduce your pain so that you can go back to doing your usual activities.

Because we do not know the cause of vulvodynia, and because there are many factors that may cause your symptoms, your treatment plan is likely to include more than one type of therapy.

### **Comfort measures**

Comfort measures are things you can do to decrease irritation, itching, and pain to your vulva. We have created a handout with information on comfort measures that you can read online at: [bit.ly/MM-ComfortMeasuresVulvarDisease](http://bit.ly/MM-ComfortMeasuresVulvarDisease).

### **Numbing medications**

Numbing medication, such as lidocaine gel or cream, helps to decrease the feeling of pain. You can get this over-the-counter, or this may be prescribed by your provider. You can put it on the skin of your vulva:

- Before sexual activity
- Overnight (usually by placing a cotton ball soaked with lidocaine gel in your vaginal opening)

Do not use other numbing creams that contain benzocaine, such as Vagisil®, because they can cause irritation, itching, and even an allergic reaction.

### **Prescription compounded medications**

A pharmacist with special training can **compound** (mix) 1 or more prescription medications into a cream or ointment that you can put on your skin. These types of medications can often help with vulvodynia nerve pain. Types of medications that may be compounded are:

- Numbing medications (anesthetics)
- Antidepressants
- Anticonvulsants
- Muscle relaxants

### **Tricyclic antidepressant medications**

We may prescribe you **tricyclic antidepressants**. These medications were first created to treat depression, but they can also treat chronic pain conditions.

Tricyclics that are commonly used to treat pain include:

- Amitriptyline (Elavil®)
- Desipramine (Norpramin®)
- Nortriptyline (Pamelor®)

When you start taking these medications, we will give you a schedule for slowly increasing the dose.

- Do not skip doses. You must take this medication every day for 3-6 weeks before you will feel its full effect.
- If you decide to stop taking this medication, do not stop taking it all at once. We will give you a schedule for slowly reducing your doses before you stop taking it completely.

### **Other antidepressant medications**

We may prescribe other antidepressant medications (that are a different type than the tricyclic medications) to help with your vulvodynia. For example, duloxetine (Cymbalta®) has been approved to treat pain.

## **Anticonvulsant medications**

**Anticonvulsant medications** were first approved to treat epilepsy (a seizure disorder), but they are now also prescribed to treat some chronic pain conditions like vulvodynia. Anticonvulsants that are commonly used to treat pain include:

- Gabapentin (Neurontin®)
- Pregabalin (Lyrica®)

When you start taking these medications, we will give you a schedule for slowly increasing the dose.

- Do not skip doses. You must take this medication every day for 3-6 weeks before you will feel its full effect.
- If you decide to stop taking this medication, do not stop taking it all at once. We will give you a schedule for slowly reducing your doses before you stop taking it completely.

## **Pelvic floor physical therapy**

**Pelvic floor physical therapy** can be an important part of your treatment plan, done by physical therapists with special training. They will talk with you first before you start any physical therapy, and they will work with your needs. You will get a treatment plan made specially for you that may include one or more of the following:

- Biofeedback
  - This is a mind-body technique to help you relax your muscles and control your breathing.
- Massage
- Electrical stimulation
  - This therapy sends electrical pulses through your skin into your muscles to help reduce pain.
- Soft tissue or joint mobilization

- This involves working on range of motion and positioning to decrease your pain.
- Relaxation exercises
- Ultrasound
  - This uses soothing heat for relief in your pelvic floor and helps to relax pelvic floor tension.

## **Counseling**

We encourage counseling for anyone with depression or anxiety, including patients who have vulvodynia. We also recommend talking with a sexual health counselor.

- Vulvar pain can affect sexual feelings and sexual functioning for both you and your partners. It is normal to move away from things that hurt, but sometimes you may get into a pattern of avoidance that makes it hard to feel sexual desire and have sexual relationships. We want you to know that, along with treating your vulvodynia, any problems you have with sexual desire, functioning, or intimacy can be addressed and often healed.

Some options for seeing a sexual health counselor include:

- Seeing a therapist during a visit at the Michigan Medicine Vulvar Diseases Clinic
- Contacting, or being referred to, the University of Michigan Center for Sexual Health. You may contact the clinic online at [www.uofmhealth.org/conditions-treatments/sexual-health/make-an-appointment-sexual-health](http://www.uofmhealth.org/conditions-treatments/sexual-health/make-an-appointment-sexual-health) or by phone at (734) 763-4963.
- Finding a certified sex therapist through the American Association of Sexuality Educators, Counselors and Therapists (AASECT) at [www.aasect.org/referral-directory](http://www.aasect.org/referral-directory)



## Injections


For people with localized vulvodynia, we may recommend an injection (shot) of numbing medication directly into the area that is painful. These may include:


- **Trigger point injections:** These are shots into painful knots in your muscle. Sometimes, we may add a steroid medication. These shots usually give short-term relief, meaning that they don't last forever and they may need to be repeated.
- **Botox® injections:** We may recommend botulinum toxin A injections, or Botox®, to help relax the pelvic floor muscles and improve your symptoms. We will do these injections in the office (you may or may not have IV sedation, or a medication to help relax you or make you sleepy) or sometimes in the operating room. This treatment is often used with other medications and pelvic floor physical therapy.
  - If Botox® works for you, sometimes you may need repeated injections to continue to improve your symptoms.

## Surgery

Rarely, if you only have pain in the vestibule and other treatment options have failed, we may suggest surgery. This involves removing all or part of the vestibule and then covering the area with vaginal tissue.

## Where can I find more information about vulvodynia?

Resource	QR code
National Vulvodynia Association: The mission of the NVA, a non-profit created in 1994, is to help improve the health and quality of life for women with vulvodynia. <a href="http://www.nva.org">www.nva.org</a>	

Resource	QR code
International Society for the Study of Vulvovaginal Disease <a href="http://www.issvd.org/resources/vulvodynia">www.issvd.org/resources/vulvodynia</a>	

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