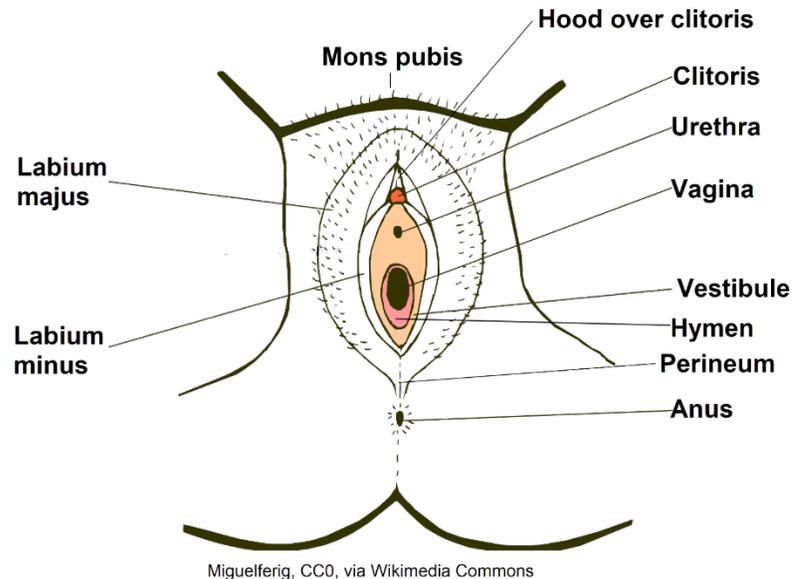


## What is Vulvodynia?

**Vulvodynia** is pain that has been present anywhere in the vulva for more than 3 months with no clear cause.

The **vulva** is the part of the body that includes all the external female genital parts from where pubic hair grows (mons pubis) to the opening that stool comes out of (anus). In between are 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).



At some time in their lives, many women will have vulvar pain with a clear cause that will go away after treatment or with time to heal. Two examples are:

- Pain from a tear caused by vaginal delivery
- Pain caused by genital herpes infection

Vulvodynia is different because the pain does not go away with time and there is no clear cause.

## What causes vulvodynia?

There are some factors that are associated with vulvodynia, but research is lacking on whether or not any of these factors definitely causes vulvodynia.

The factors are:

- **Genetics:** a family trait passed from parent to child)
- **Hormones:** For some women, using a contraceptive pill can increase the risk of getting vulvodynia. This may be because your genetics cause increased sensitivity to hormones in contraceptive pills.
- **Inflammation** (the body's response to injury, infection, or disease): For some women, the normal response to infection or injury is much stronger and lasts longer than is needed or expected. Some women with vulvodynia have certain types of cells that lead to inflammation. These have been found in tissue taken from painful areas in the vulva.
- **Musculoskeletal:** Pelvic muscle weakness, tightness or instability can cause vulvar pain. On the other hand, your pelvic muscles may tighten and spasm as a way for your body to protect itself.
- **Neurological:**
  - Changes in the brain can turn what would normally be felt as mild pressure or irritation into a feeling of severe pain. This can be present in other parts of your body in addition to your vulva.
  - Some women with vulvodynia have an increase in the number of nerve endings that feel pain. This has been found in pieces of skin (biopsies) removed from the vulva.
- **Other pain syndromes**

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

  - Fibromyalgia
  - Irritable bowel syndrome
  - Orofacial (mouth, jaw, and face) pain
  - Painful bladder syndrome (interstitial cystitis)
- **Psychosocial**
  - Vulvodynia is not caused by anxiety and it is not an imagined pain. However, women with vulvodynia are more likely to have anxiety, depression, and post-traumatic stress disorder (PTSD). The psychological disorders may be both a cause of vulvodynia and a result of chronic pain.

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- Your mindset about pain is formed by your family, community, and individual personality. For one person, pain may be a hassle that requires some changes in daily habits. For another, it may be an overwhelming catastrophe that will prevent life from ever being enjoyable again. Your mindset affects how severely you feel pain and its impact on your daily life. See the handout here for an in-depth explanation of handling pain: <http://www.med.umich.edu/1libr/psych/PainMindBodySpirit.pdf>
- Your family's mindset, especially that of a current or possible future sexual partner, also has a strong impact on how vulvodynia affects you.

It is most likely that vulvodynia is related to, or worsened by, more than one of these factors, and the mix of factors that most affects you is not necessarily the same as someone else.

If future research shows a cause that can be successfully treated, then women with the particular cause would have a newly defined kind of vulvar pain and no longer have vulvodynia.

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

To best understand your pain we need to know:

- **What does it feel like?**  
Vulvodynia pain is often described as burning, but may also feel sharp, pressure, aching, or something else.
- **Where is it located?**  
It may include the entire vulva or may involve only a smaller specific area. We may ask you to shade in the part of a drawing of the vulva where you feel pain.
- **What causes or worsens pain?**
  - **Spontaneous** pain is an unpredictable pain that can occur at any time.
  - **Provoked** pain is a pain that happens only when there is pressure on the vulva, for example from wearing tight clothes, using a tampon, or sexual activity. We will want to know if this was there from the first time you tried to use a tampon or have sex, or if it started later in your life.
- **How long does the pain last?**  
Pain may be constant and unchanging. For provoked pain, it may stop soon

after the activity causing pressure is stopped. Over days, weeks, and months the pain may have the same pattern, may sometimes go away, or get less severe without any reason you can find.

### **How is it diagnosed?**

Vulvodynia is a diagnosis of **exclusion**, meaning that we first have to check for (exclude) known causes of vulvar pain. We will do an exam and may use a small swab or Q-tip to collect a sample for a yeast culture or other tests. We may need to remove a small piece of skin (biopsy) to send to the laboratory to check for diseases that can be diagnosed and treated. We will give you a shot of numbing medicine before the skin is removed. If no infection or disease is found then the diagnosis is vulvodynia.

### **How is it treated?**

The goal of treatment is to make your pain symptoms go away or to at least decrease them to a level that allows you to resume your usual activities.

Vulvodynia is difficult to treat and it is not unusual to need long-term treatment that can last weeks, months, or even years.

Because we do not know the cause of vulvodynia and there are many factors that may play a role in causing your symptoms, your treatment plan is likely to include more than one type of therapy. Treatment options include:

#### **Comfort measures**

Follow the comfort measures described in:

- “Comfort measures for all diseases: what you can do to prevent vulvar irritation and itching” section of the “Vulvar Diseases” booklet:  
<https://michmed.org/G2qq3>
- “Comfort Measures to Decrease Vulvar Irritation, Itching, and Pain”:  
<https://michmed.org/O5v80>

#### **Medications**

**Prescription numbing medication** such as lidocaine gel or cream may need to be applied to the skin:

- Before sexual activity

- Overnight, usually by placing a cotton ball soaked with lidocaine gel in the vaginal opening

**Note:** Do not use over-the-counter numbing creams that contain benzocaine, such as Vagisil<sup>®</sup>, because they can cause irritation, itching, and even an allergic reaction.

### **Prescription compounded medications**

A pharmacist with special training compounds (mixes) one or more medicines into a hypoallergenic base cream or ointment that is applied to the skin.

Types of medicines that may be included are:

- Numbing (anesthetic)
- Antidepressant
- Anticonvulsant
- Muscle relaxant

**Tricyclic antidepressant medications** were first approved to treat depression, but can also treat chronic pain conditions.

Tricyclics that are commonly used to treat pain:

- Amitriptyline (Elavil<sup>®</sup>)
- Desipramine (Norpramin<sup>®</sup>)
- Nortriptyline (Pamelor<sup>®</sup>)

You will receive a schedule for gradually increasing the dose.

- Do not skip doses. Medication must be taken daily for 3 to 6 weeks before you will feel its full effect.
- Do not stop all at once. We will give you a schedule for gradually weaning off before stopping altogether.

### **Other antidepressant medications**

Other antidepressant medications that are in a different class than the antitricyclic medications may also be used. Duloxetine (Cymbalta<sup>®</sup>) has been FDA approved to treat pain.

**Anticonvulsant medications** were first approved to treat epilepsy, but are also FDA-approved to treat certain chronic pain conditions.

Anticonvulsants that are commonly used to treat pain:

- gabapentin (Neurontin®)
- pregabalin (Lyrica®)

You will receive a schedule for gradually increasing the dose.

- Do not skip doses. Medication must be taken daily for 3 to 6 weeks before you will feel its full effect.
- Do not stop all at once. We will give you a schedule for gradually weaning off before stopping altogether.

### **Injection of numbing medicine or trigger point injections**

If your pain is only in a well-defined part of the vulva, we may give you an injection (shot) to numb this area. Sometimes, a steroid medicine to reduce inflammation is added. This usually gives short-term relief and may need to be repeated.

### **Pelvic floor physical therapy**

Important part of treatment plan for many women.

- Done by physical therapists with specialized training. They will talk with you first and are sensitive to your needs.
- You will get a treatment plan made specially for you that may include one or more of the following:
  - Biofeedback
  - Massage
  - Electrical stimulation
  - Soft-tissue or joint therapy
  - Ultrasound
  - Relaxation exercises

### **Counseling**

We encourage counseling for anyone with depression or anxiety. Beyond this, we know that vulvar pain can affect sexual feelings and sexual functioning for both you and your partner. 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 your vulvodynia, problems with sexual desire, functioning, or intimacy can be addressed and healed.

Arrange therapy with a sexual health counselor by:

- Seeing a therapist during a visit at the Michigan Medicine Vulvar Diseases Clinic
- Contacting, or asking to be referred to the University of Michigan Center for Sexual Health: (734) 763-4963
- Finding a certified sex therapist through the American Association of Sexuality Educators, Counselors and Therapists at <https://www.aasect.org/referral-directory>.

### **Botox Injections**

Depending on your history and our exam, we may recommend Botulinum Toxin A (Botox) injections (shots) to help relax the pelvic floor muscles and improve your symptoms. We can give you the Botox injections in different settings:

- A regular clinic exam room
- A clinic procedure room where we can give you IV sedation
- An operating room where we can give you anesthesia (not often needed)

If a Botox injection reduces your pain, you may benefit from a series of injections. We usually combine Botox injections with oral or topical (skin) medication and pelvic floor physical therapy.

### **Surgery**

If other methods have failed to treat pain located only in the vestibule, we may offer surgery . This involves removing all or part of the vestibule and then covering the area with vaginal tissue.

### **Resources**

Education booklets and other resources for patients (National Vulvodynia Association)

- Self-Help Guides: <https://www.nva.org/publications/self-help-guides/>
- Online patient tutorial: <https://www.nva.org/learnpatient/>

- How NVA Can Help You: <https://www.nva.org/for-patients/>

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.

Disclaimer: This document contains information and/or instructional materials developed by 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.

Author: Diana Stetson PA-C  
Reviewers: Kathryn Welch MD

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