IC and Vulvodynia

The term vulvodynia (pronounced vulvo-DIN-ee-ah) means pain in the vulva—the female external genital organs. The condition is very common in women with IC. Vulvodynia can make sex or any other activity that puts pressure on the area painful—prolonged sitting, bicycle or horseback riding, inserting a tampon, or even wearing fitted pants. Many treatments are available that can ease this pain and help you regain physical activity and a satisfying sex life.

Types of Vulvodynia

There are two main types of vulvodynia, which sometimes co-exist:

- **Vulvar vestibulitis syndrome (also called provoked vestibulodynia)**
  - In this type, pain is limited to the entrance to the vagina, the vestibule or vestibulodynia
  - This syndrome is often accompanied by burning, stinging, or itching sensations in the vulvar skin or underlying tissues, and the presence of a skin lesion or inflammatory changes.

- **Generalized Vulvodynia**
  - In this type, pain may be located in the vestibule or other areas of the vulva, such as the labia, clitoris, perineum, or inner thighs. The pain occurs spontaneously and may be constant, but it can be aggravated by activities that put pressure on the area, such as prolonged sitting or wearing fitted pants.

What Causes Vulvodynia in IC Patients?

Although the precise cause is not known, some researchers speculate that vulvodynia and IC are closely related because the bladder, urethra, and vulvovaginal tissues have a common embryonic origin. These structures are also surrounded and supported by the same muscles, and the nerves that serve them communicate with the same areas of the spinal cord. Some of the proposed causes of vulvodynia include:

- nerve injury or irritation or increased density of nerve fibers
- allergies or sensitivities
- inflammation
- abnormal tissue response to infection, trauma, or substances in the environment
- hormonal changes
- genetic susceptibility to pain or vulvar inflammation
- hypersensitivity to yeast (Candida) or other organisms
- pelvic floor muscle dysfunction

How is Vulvodynia Diagnosed?

Your provider will take a thorough medical history, ask about your symptoms, and examine your vulva, vagina, and vaginal secretions carefully. The hallmark of vulvodynia is sensitivity to touch, which your provider will test with a cotton-tipped swab. He or she will gently apply pressure to various parts of your vulva and ask how it feels.

Your provider may also examine the tissue through a magnifier or take a specimen for biopsy. Examination and cultures will help rule out bacterial or yeast infections or skin disorders. Blood tests will help determine whether hormone levels may play a role.

How is Vulvodynia Treated?

Because vulvodynia not only causes pain but also affects your daily activities, your relationships, and your mental health, getting better may take a combination of self-help techniques, medical treatments, and psychological support. That’s why you may need a multidisciplinary team of providers to help you, such as a gynecologist or vulvovaginal specialist, a dermatologist, a physical therapist, and a sex or couples therapist or psychologist.

No one treatment or combination works for everyone, so be sure you have a give-and-take with your providers about what helps, what doesn’t, and what you need.

**Self-help techniques**

**AVOID IRRITANTS**

Detergents, fabric softeners, toilet paper, certain underweard, pads or tampons, and soaps or creams may be irritating, so avoid bleach, fabric softener, douches, contraceptive creams or foams, and hot tubs or pools with chlorine. Try nonirritating, unscented detergent, paper products, and toiletries, and wear all-cotton underwear. After urinating, use a squirt bottle or bidet to rinse with cool water. Dry gently.

**TAKE THE PRESSURE OFF**

Wear loose-fitting pants or skirts, sit on a cutout cushion, avoid cycling and horseback riding, use nonirritating lubricants for sex, learn lovemaking techniques that minimize irritation (see our brochure Sex and IC), and learn lovetaking techniques that minimize irritation (see our brochure Sex and IC).

- [Learn more at www.ichelp.org/LivingWithIC](http://www.ichelp.org/LivingWithIC)

**AVOID DIET TRIGGERS**

The items that provoke your bladder may also affect vulvodynia. Some also suggest a low-oxalate diet. Everyone is different, so use an elimination diet to find out which dietary items affect you.

- [Learn more at www.ichelp.org/Diet](http://www.ichelp.org/Diet)

**SOOTHE YOUR BODY AND MIND**

Apply heat or cold, whichever feels helpful at the time, with warm or cool baths or sitz baths, oatmeal baths, warm or cold packs or packs on the vulva, or something that can be safely warmed or cooled and inserted in the vagina, such as certain adult recreational products or the finger of a medical glove filled with chilled or warm water. Relaxation, visualization, or meditation can also help.

**ORAL MEDICATIONS**

Pain relieving medications include tricyclic antidepressants, serotonin-norepinephrine reuptake inhibitors (SNRIs), anticonvulsants, and opioids. Antiinflamgs for yeast or antihistamines may be helpful.

Become Part of the ICA Community

Annual membership donations to the Interstitial Cystitis Association ensure a steady stream of funding to fuel advocacy activities, expand research funding, and raise awareness about IC.

For an annual contribution of $45.00 or more ($75.00 outside of the US) you will become a part of the ICA community and receive an ICA Patient Education Kit with information about IC, treatment options, research initiatives, and a restroom access card.

As an ICA member, you also receive:

- [Award-winning, quarterly magazine-ICA Update](http://www.icaupdate.org)
- [News and research updates via the ICA eNews](http://www.icaenews.org)
- [A 50% discount on materials in the ICA Store](http://www.ica.org/store)
- [Discounted registration rates for ICA patient forums and other events](http://www.ica.org/events)

To join, send a check or money order (US funds only) made payable to ICA with this form to the address indicated below or join online at [www.ichelp.org/membership](http://www.ichelp.org/membership).

Deductions to the ICA are tax-deductible to the fullest extent allowable by law.

Keep the dialogue going

Help others understand the need to find REAL answers about IC!

Please make your donation in US funds only.

Please do not send cash.

The ICA does not engage in the practice of medicine. It is not a medical authority nor does it claim to have medical knowledge. In all cases, the ICA recommends that you consult your own physician regarding any course of treatment or medication.
About the ICA

The Interstitial Cystitis Association (ICA) is the only nonprofit health association dedicated to improving the quality of healthcare and lives of people living with interstitial cystitis (IC).

Conquering IC. Changing Lives.

The ICA provides advocacy, research funding, and education to ensure early diagnosis and optimal care with dignity for people affected by IC. Our work is made possible through the generosity and vision of individuals as well as of foundations and corporations.

Donations help us to keep programs and services operating at peak strength so that every IC patient who needs help can have it—no matter where he or she may live, no matter how disabled they may be.

Your donation dollars also enable the ICA to continue to fund new IC research projects as well as to work closely with Congress to ensure ongoing federal funding of IC-specific research.

Helpful Links
- www.ichelp.org/AboutIC
- www.ichelp.org/Vulvodynia

The information provided by the ICA is designed to support, not replace, the relationship that exists between an individual and his/her healthcare provider.

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TOPICAL MEDICATIONS
These may include topical lidocaine or hormones or other medications that may need to be compounded into creams, gels, or suppositories, such as muscle relaxants, anticonvulsants, mast cell stabilizers, capsaicin, and other medications.

INJECTIONS
Injection of anesthetics or other medications beside nerves that serve the vulva or into pelvic muscle trigger points can be done in a doctor’s office. Onabotulinumtoxin A (Botox) injected into the vestibule, pelvic floor muscles, and other vulvar sites is beginning to be used as a treatment. Interferon injections are sometimes used for vulvar vestibulitis.

PHYSICAL THERAPY
Pelvic floor therapy should be aimed at relaxing, not strengthening, the pelvic floor muscles as well as releasing muscle trigger points, connective tissue restrictions, and nerves.

INTERVENTIONAL THERAPY
For more severe pain, spinal cord or peripheral nerve stimulators or pumps that release pain medications into the spinal canal can be implanted.

SURGERY
Women with severe vulvar vestibulitis may be candidates for vestibulectomy, a surgery that removes some or all of the vestibule.