

Vulvodynia: A Self-Help Guide



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Association

www.nva.org

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The National Vulvodynia Association is not a medical authority and strongly recommends that you consult your own health care provider regarding any course of treatment or medication.

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Introduction

Welcome to the NVA's self-help guide for women with vulvodynia. We created this guide to answer many of your questions about vulvodynia and its treatment, and to offer suggestions for improving your quality of life. First we'd like to highlight a few important points.

Each woman's experience with vulvodynia is unique, with symptoms ranging from mild to incapacitating. If your pain level is mild, some of the information in this guide may not apply to you.

Some doctors are still unfamiliar with vulvodynia. Many women spend a long time wondering what is wrong with them and see several doctors before they are told they have vulvodynia. An accurate diagnosis is half the battle, so now you can focus your efforts on finding helpful treatments and feeling better.

When you start a new treatment, try to be patient and hopeful. There are many treatment options for vulvodynia and no single treatment works equally well for all women. Sometimes progress is slow and you may only notice improvement on a monthly, rather than daily, basis.

It is important to participate in treatment decisions and discuss your progress (or lack of it) with your doctor or other health care provider. You know more about how you feel than anyone else.

Finally, as you read through this guide, we recommend that you take notes on topics you would like to discuss with your provider.

So, with the above in mind, let's begin!

***This guide was written for every woman
with chronic vulvar pain who thought
that she was suffering alone.***

- Phyllis Mate, NVA co-founder

Section I: Learning the Basics

Gynecological Anatomy

You may recall learning about the facts of life, but do you remember being taught about your vulvovaginal anatomy? Most women don't and it certainly didn't help that body parts below the belly button were referred to as "down there." Many women don't realize that the vulva and vagina are composed of different tissue and exhibit different problems. The distinction between the vagina and vulva is comparable to that of the mouth and the lips. If you have chapped lips, you apply lip balm to the surface of your lips and not inside your mouth. The same applies to a vulvar disorder, i.e., you don't insert medicine into the vagina to treat a condition of the external tissue. On the other hand, if you are diagnosed with a vaginal disorder, such as a yeast or bacterial infection, you should insert medicine into the vagina.

The vulva is the *external* part of the female genital area.

The vulva protects a woman's vagina, urinary opening and vestibule, and is the center of much of a woman's sexual response. The mons pubis, located above the vulva, is the tissue covering the pubic bone. The outer and inner 'lips' of the vulva are called the *labia majora* and *labia minora*. The *clitoris*, located above the opening to the vagina, is a source of female sexual excitement. The *vestibule* surrounds the opening of the vagina, or *introitus*, and the opening of the urethra, or *urethral meatus*. The *perineum* is the area extending from beneath the vulva to the anus.

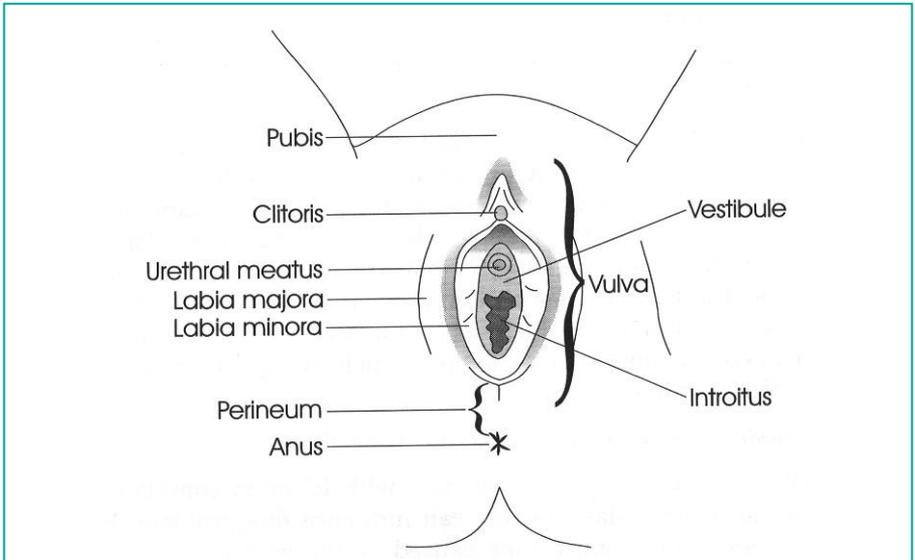


Diagram reproduced with permission from *The Interstitial Cystitis Survival Guide* by Robert Moldwin, MD, New Harbinger Publications, Inc. © 2000.

The vulva and vagina are composed of different tissue.

The vagina is a passageway beginning at the vaginal opening and ending inside the body at the *cervix*, the lowermost part of the uterus. The *bladder* sits directly in front of the vagina and the *rectum* is located behind it. The width and length of the vagina vary among women.

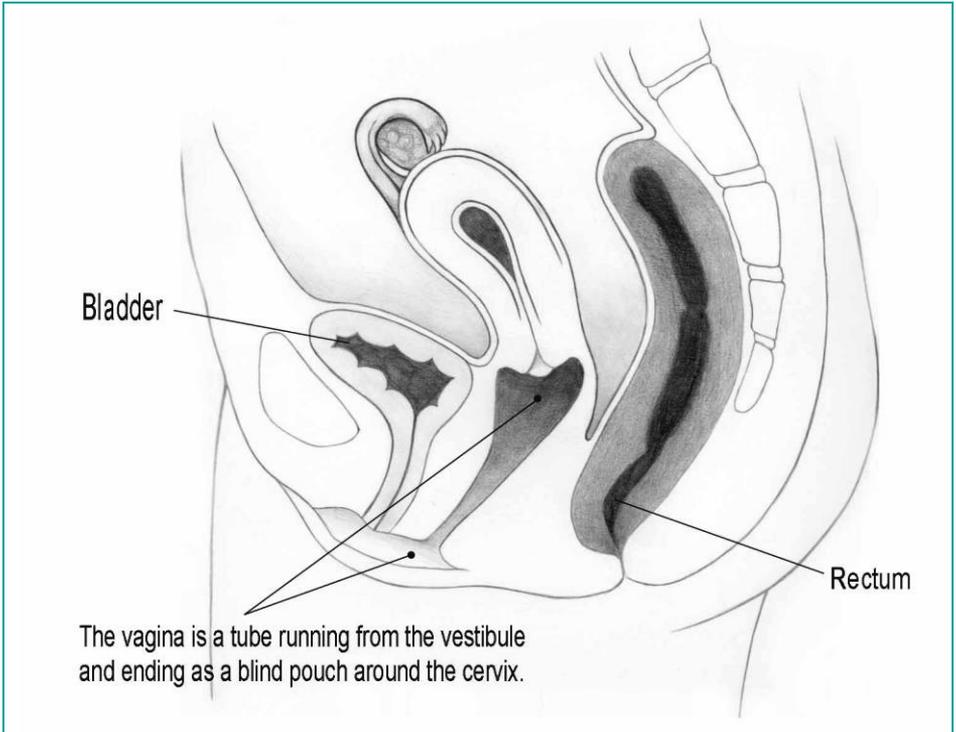


Diagram reproduced with permission from The V Book by Elizabeth D. Stewart, MD and Paula Spencer (Illustrations by Dawn Danby and Paul Waggoner), Bantam Books, 2002.

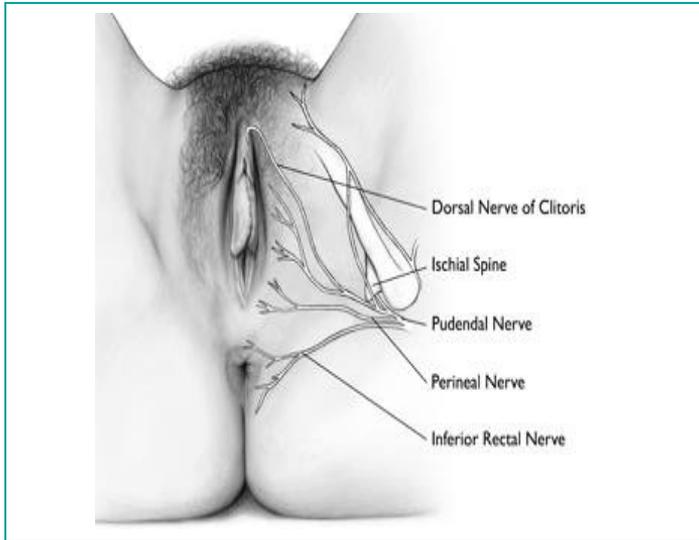
The vagina is composed of unique tissue that can expand and contract. It serves many functions, such as accommodating the penis during sexual intercourse, expanding to allow childbirth, providing access to examine the cervix and preventing harmful bacteria from entering the body.

I learned so much about pelvic anatomy from your guide. I'm embarrassed to admit that I didn't even know what the vulva was until now.

- Emily Warren, Philadelphia, Pennsylvania

The pudendal nerve transmits pain messages and other sensations from the vulva.

The pudendal nerve originates from the sacral spine, which is located immediately below the low back area. The nerve passes through the pelvis and enters the vulvar region near the ischial spine, which is part of the hip bone. From there, it branches into the inferior rectal nerve, perineal nerve and dorsal nerve of the clitoris. The pudendal nerve is responsible for proper functioning and control of urination, defecation and orgasm in both males and females.



Courtesy of Dawn Danby

The pelvic floor muscles support the reproductive organs.

The pelvic floor is composed of pelvic organs, muscles, nerves and ligaments. Having strong pelvic floor muscles helps with trunk stability and mobility. The pelvic floor muscles work cooperatively to aid in bladder, bowel, sexual and respiratory function.

As demonstrated in the bottom figure on page 5, the pelvic floor muscles are divided into two categories. The lightly shaded superficial muscles, collectively known as the *urogenital triangle*, are the bulbocavernosus, ischiocavernosus, and transverse perineum. The darker-shaded deep muscles, sometimes called the *anal triangle*, include the levator ani and coccygeus muscles. Other associated muscles are the obturator internus and piriformis.

Illustration #1-Female Urogenital System (midsagittal section)

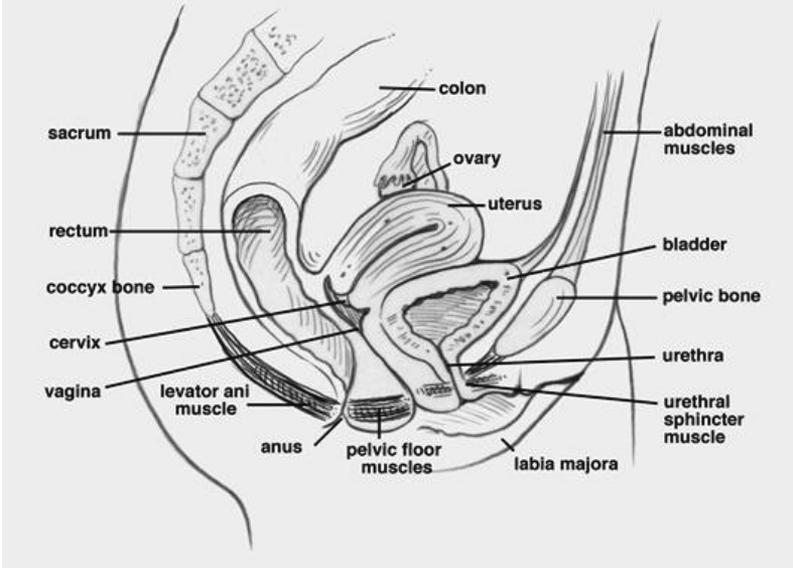
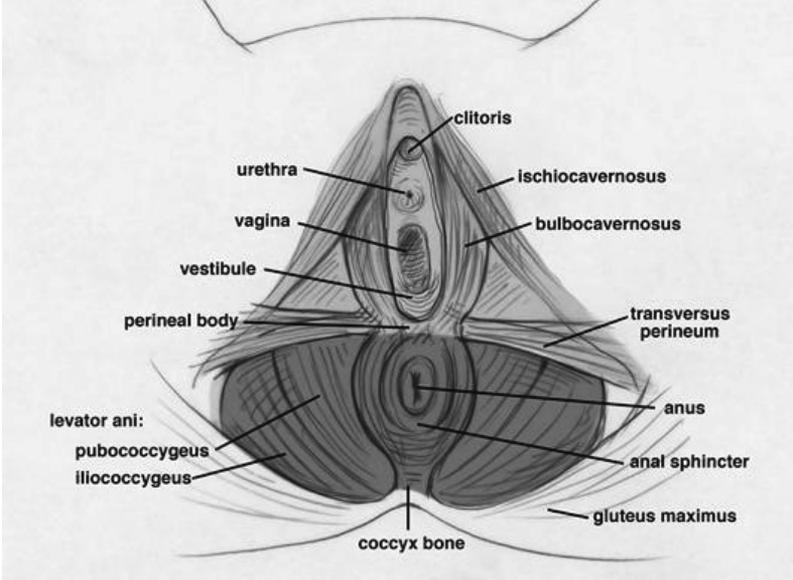


Illustration #2 Female Pelvic Floor Anatomy



*Diagrams reproduced with permission from
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Normal and Abnormal Vulvovaginal Symptoms

Each woman's body is unique, including the appearance of the vulva. Vaginal secretions and odor vary among women as well. Sometimes it is difficult to figure out which characteristics are normal and which are not. Below is a summary of vulvovaginal characteristics and disorders that should help to illustrate the difference. If you notice any abnormalities, consult your health care provider promptly and resist the temptation to self-treat.

Vulvar Skin Color and Texture

The labia majora (outer lips) protect the inner parts of the vulva and their color is similar to your overall skin color. They are covered with pubic hair and contain many sweat- and oil-secreting glands. Beneath them is a layer of protective fat that cushions during sexual intercourse. Located between the labia majora are the labia minora (inner lips), which vary in color from a deep pink to a brownish or reddish pink. They can either be thin, small flaps or thick, bumpy bulges. The inner surface of the labia minora is smooth and moist. Along the edges of these inner lips are glands that cause a pebbly appearance, similar to tiny pimples. Situated at the base of the labia minora is the vestibule, the tissue surrounding the vaginal opening. The vestibule is moist and pink, but sometimes it may appear almost red. The clitoris is located above the urethra where the labia minora meet and is covered by a hood that can be pulled back to expose it.

Bumps and color changes may occur in the vulva and can either be completely harmless or indicate a problem. Trying to diagnosis them on your own is extremely difficult, so if you notice a bump or discoloration, you should consult your health care provider promptly.

Vaginal Discharge

Vaginal secretions result from multiple sources, including cells shed from the vaginal walls, mucus from the cervix and secretions of specialized glands, such as Bartholin's and Skene's. Some vaginal discharge is normal and the amount changes with hormonal status, i.e., it varies at different stages of the menstrual cycle. An increase occurs mid-cycle during ovulation and just afterwards. The color of the discharge also changes during the menstrual cycle, ranging from clear to milky white or faintly yellow. If you take oral contraceptives, the volume of discharge does not vary over the course of the month, because the pills maintain steady levels of the female hormones estrogen and progesterone. Since women differ in their amount of discharge, it is important to become familiar with what is normal for you.

Vaginal discharge is mildly acidic, which helps protect the vagina from infection. It is important to remember that normal secretions do not itch,

burn or irritate, nor do they smell like fish or ammonia. Abnormal discharge varies in its amount and appearance. Secretions may become more profuse, cause a strong odor, change in color (from clear to gray-white, yellow-white or yellow-green), and/or contain traces of blood, if inflammation is severe.

Odor

The vulva contains a large number of sweat-producing glands. Sweat allows heat to escape and is a source of odor. Some vulvovaginal odor is normal, but if it's unusually strong, it can be treated. Normal vaginal secretions may have an odor that changes over the menstrual cycle, not have any odor or smell faintly like sour milk. Each woman has a unique scent. Vaginitis, or vaginal inflammation, is the most common reason for an unpleasant and abnormal odor. Bacterial vaginosis (BV) is the likeliest suspect, because it elevates the normally acidic pH of the vagina, causing an odor of ammonia, in mild cases, or dead fish, in severe cases. Trichomoniasis may also cause a fishy odor. Yeast is a less common cause of unpleasant odor.

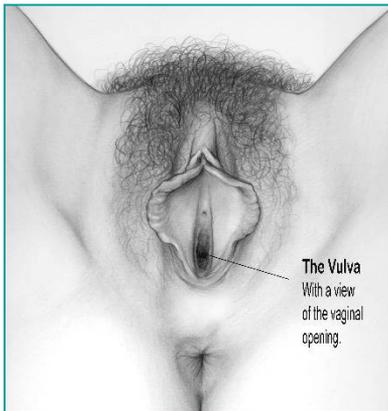
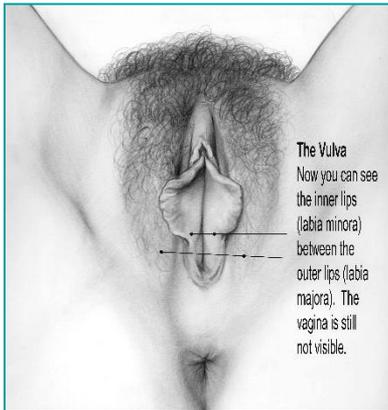
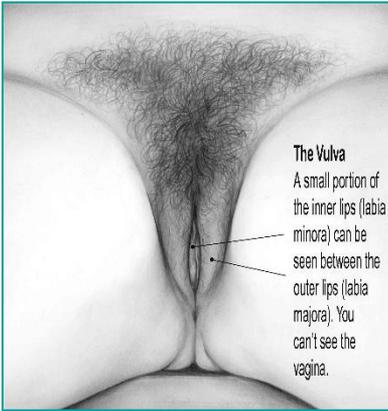
Changes with Pregnancy and Childbirth

During pregnancy, vaginal secretions may increase, have a thicker consistency and appear bluish-violet in color. If your discharge turns watery, you should be evaluated, because it is possible that the cervix has weakened, resulting in leakage from your water bag. Some women also develop varicose veins in the vulvar area, which can be quite uncomfortable. If you have a vaginal delivery, the vaginal opening will temporarily appear larger. Also, if an episiotomy or tear occurs during delivery, you may have a visible perineal scar (between the vaginal opening and the anus). During the postpartum period, estrogen levels are very low, especially in women who breastfeed their babies, causing a lack of vaginal lubrication. To protect the vulva in the weeks following delivery, providers advise women to abstain from sexual intercourse for at least four to six weeks.

Changes with Menopause

During perimenopause (five to ten years before menopause), you may experience vaginal dryness or itchiness, discomfort with intercourse, and/or an increase in yeast or bacterial infections. Due to the lack of estrogen during menopause, vulvar skin usually becomes thinner and drier. Additionally, the labia minora may flatten or shrink and the vaginal opening may appear smaller. Vaginal tissue may become thin and dry, making intercourse uncomfortable or painful. Eventually, discharge becomes minimal or disappears, except in women who take hormone replacement therapy, are heavy in weight, or take certain medications, such as tamoxifen.

Vulvar Self-Examination



Diagrams reproduced with permission from Dawn Danby and Paul Waggoner.

Although many women perform breast self-examination, few have heard about vulvar self-examination (VSE). As previously mentioned, the appearance of the vulva varies among women. Between routine gynecological examinations, you should perform VSE to detect abnormalities that may indicate infection or disease. It is important to start performing VSE at an early age, so you can learn what is normal and then recognize any changes. You should not experience discomfort from your VSE, unless you have a vaginal infection, open sore or other vulvar condition.

How to Perform VSE

Wash your hands and then perform VSE in a well-lit area. Sit down on a comfortable surface or stand with one foot propped up on a chair or bed. Hold a mirror in one hand and use the other hand to examine the vulva.

Examine the parts of the vulva using sight and touch: the mons pubis; the left and right folds of the labia majora and minora; the clitoris and its general area; the skin around the vaginal opening; the perineum; and the perianal area.

What to Look for During Your VSE

Do you see a new mole, wart, lump or other growth? Is there a change in skin color, e.g., white, reddened or brown patches? Are there any cuts or sores?

Is there a change in the way the vulvar skin feels? Pay careful attention to areas that elicit pain, itching or other discomfort. Check for lumps by applying gentle pressure to the skin.

When to Examine

Vulvar self-examination should be done monthly, preferably in the middle of the cycle. All sexually active women and women over 18 should perform VSE. If you notice any changes, you should contact your provider promptly.

Section II: Understanding Vulvodynia

What is Vulvodynia?

Vulvodynia is vulvar pain of at least three months duration, without a clear identifiable cause. The location, constancy and severity of the pain vary among sufferers. Symptoms also vary, but most women describe the pain as a burning sensation. Others report stinging, rawness and irritation. Fewer women describe it as a sharp sensation, “like a knife is piercing the vulva.”

There are two main categories of vulvodynia:

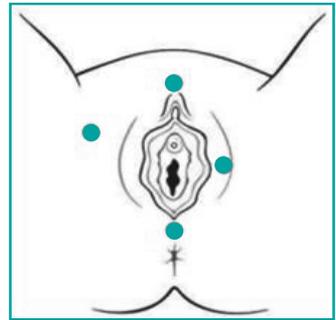
- **Localized Vulvodynia**

Many women have pain at only one vulvar site. If the pain is in the vestibule, the tissue surrounding the vaginal opening, the diagnosis is *Vestibulodynia*. (See diagram on the right.) The majority of women with localized vulvodynia have *Provoked Vestibulodynia (PVD)*, in which pain occurs only with touch or pressure, e.g., intercourse, gynecologic exams, tight pants or sitting. A less common form of localized vulvodynia, known as *clitorodynia* (pain in the clitoris), may be very painful.



- **Generalized Vulvodynia**

In this subtype, pain is felt over the entire vulva or at multiple sites. (See diagram on the right.) The pain is spontaneous and relatively constant, but there are usually some periods of relief. Once a gynecologist diagnoses you with generalized vulvodynia, it may be very helpful to see a pain management specialist or a pain anesthesiologist.



Most women have either localized or generalized vulvodynia, but if you have symptoms of both types, it is known as *mixed vulvodynia*.

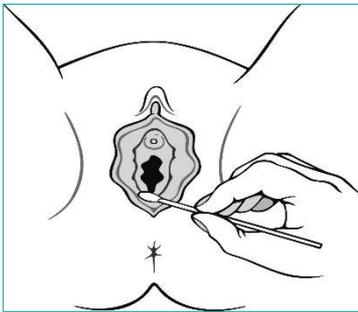
What Causes Vulvodynia?

Vulvodynia is not caused by an active vulvovaginal or sexually transmitted infection and is not a contagious disease. Through continued research efforts, we are moving closer to learning the cause(s) of vulvodynia. Researchers propose that one or more of the following may cause, or contribute to, vulvodynia:

- An injury to, or irritation of, the nerves that transmit pain from the vulva to the spinal cord
- An increase in the number and sensitivity of *pain-sensing* nerve fibers in the vulva
- Elevated levels of inflammatory substances, e.g. cytokines, in the vulva
- An abnormal response of certain cell types to environmental factors, such as infection or trauma
- Genetic susceptibility to chronic vulvar inflammation, chronic widespread body pain and/or an inability to combat infection
- Pelvic floor muscle weakness, spasm or instability

How is Vulvodynia Diagnosed?

A gynecologist, urogynecologist or other provider knowledgeable about vulvodynia should perform your first examination to rule out conditions that mimic the symptoms of vulvodynia. Then, based on your symptoms, you may be referred to other specialists for continued care.



After taking a thorough medical history and asking questions about your symptoms, the provider should carefully examine the vulva, vagina and vaginal secretions to rule out an active infection or skin disorder. He/she may also recommend that you have blood drawn to assess levels of estrogen, progesterone and testosterone, and will likely perform a cotton-swab, or “Q-tip” test (pictured on the left). During the test, gentle pressure is applied to various vulvar sites and you are

asked to rate the severity of the pain. If any areas of skin appear suspicious, the provider may examine them with a magnifying instrument or take a biopsy of the area.

Co-Existing Conditions

Some women with vulvodynia suffer from one or more other chronic pain disorders, such as irritable bowel syndrome, fibromyalgia and painful bladder syndrome. Discuss all of your pain symptoms with your health care provider.

How is Vulvodynia Treated?

Vulvodynia is a multifaceted condition that (i) affects the genital area, (ii) usually involves the pelvic floor muscles, (iii) is a chronic pain condition, and (iv) may cause emotional distress. Therefore, experts favor a multi-disciplinary approach; in addition to a gynecologist, you may benefit from seeing a women's health physical therapist and pain management specialist. If you are feeling anxious, depressed or experience relationship difficulties, consulting a psychologist or couples/sex therapist is also recommended.

Because we don't know what causes vulvodynia, treatment is directed towards alleviating symptoms. Some women may respond to a certain treatment, while others do not respond or experience unacceptable side effects. It may take several months, or sometimes years, before you find a satisfactory treatment, or combination of treatments, that relieves your pain.

The most common treatments are:

Discontinuation of Irritants

Health care professionals recommend eliminating over-the-counter feminine products, such as perfumed bubble baths, soaps, sprays and douches that can irritate vulvar tissue. Eliminating irritants is typically the first step in treatment. (Please see Self-Help Strategies for Vulvar Pain on page 16.)

Some women find that eating a certain food increases their pain and that eliminating it relieves pain. For example, some women are sensitive to acidic or high-sugar foods. If you want to test for food sensitivity, eliminate one item or food group at a time to determine which one, if any, affects you.

Oral “Pain-Blocking” Medications

Medications that may be effective in alleviating other types of chronic pain are often used in the treatment of vulvodynia. They include:

- **Tricyclic Antidepressants (TCAs)**

Although TCAs were developed to treat depression, some studies have demonstrated their effectiveness in treating other chronic pain conditions. For women with vulvodynia, the recommended dosage is usually much lower than that used for the treatment of depression. To minimize side effects, it is best to start with a very low dose and increase the amount gradually; thus, it can take many weeks to months to achieve a therapeutic level. Common side effects, some of which can be managed, include drowsiness, dry mouth, dizziness and constipation. The severity of the side effects depends on which TCA you take, e.g., amitriptyline causes more adverse side effects than nortriptyline or

desipramine. If you decide to stop taking a TCA, it should be tapered gradually. Although they are still commonly prescribed, two recent controlled studies have found that TCAs do not relieve vulvodynia.

- **Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)**

SNRIs, a newer type of antidepressant, work differently than the TCAs. These medications are FDA-approved to treat depression and anxiety disorders, as well as some chronic pain conditions, such as fibromyalgia and peripheral neuropathy. SNRIs are also used “off-label” to treat other chronic pain disorders. The most common side effects, some of which improve over time, include headache, nausea, insomnia, dizziness, dry mouth and sexual dysfunction. It can take weeks or months to reach a dose that relieves pain. If you want to discontinue an SNRI, it is important to taper it slowly. Two SNRIs, venlafaxine and duloxetine, have been used to treat vulvodynia, but their effectiveness has not been proven in large controlled studies.

- **Anticonvulsants**

Medications developed to inhibit seizures are effective in controlling certain chronic pain syndromes. For example, the anticonvulsant pregabalin is FDA-approved to treat postherpetic neuralgia and diabetic neuropathy. Anticonvulsants are often prescribed for women with vulvodynia, especially when pain is described as having a “shooting or stabbing” component. There has only been one controlled study on the effectiveness of an anticonvulsant in vulvodynia patients. The researchers found that gabapentin (Neurontin) was no more effective than placebo for relieving pain. Regardless, gabapentin is the most widely prescribed anticonvulsant for vulvodynia. As with TCAs, you have to start with a low dose and increase the amount gradually. If you decide to discontinue the drug, taper the dosage slowly.

- **Opioids**

Pain-relieving opioids, such as hydrocodone or oxycodone, may be very helpful for short-term use during vulvodynia flares. They can also be used to relieve pain early in treatment, while you gradually increase the dosage of an antidepressant or anticonvulsant to a therapeutic level. In severe cases, when conservative therapies fail to provide relief, long-acting opioids may be used on an ongoing basis. Common side effects, which can usually be managed, include constipation, nausea and drowsiness. Opioids should not be discontinued abruptly if taken for a long period of time.

Topical Medications

Topical medications applied directly to the vulva may help to alleviate vulvar pain, but some preparations contain additive substances that are irritating to the skin. Therefore, many vulvodynia experts use compounding pharmacies that make topical creams and ointments without irritating additives.

Examples of topical medications include:

- **Topical Hormonal Creams (e.g., estrogen, testosterone)**

Topical estrogen cream may improve the health of vulvar tissue, particularly when it is thin or dry because of a lack of estrogen. In recent years, some experts have noted that the hormone testosterone plays a role in women's sexual health and prescribe a combination estrogen/testosterone topical cream.

- **Topical Anesthetics (e.g., lidocaine)**

Topical anesthetic cream or ointment provides temporary pain relief and is often applied directly to the vulva prior to intercourse. Typically, the numbing effect lasts 15 to 30 minutes. One study found that long-term nightly use of lidocaine resulted in sustained pain relief.

- **Topical Compounded Formulations**

Medications that are normally prescribed for oral use, such as antidepressants and anticonvulsants, can also be formulated into a cream or ointment. Topical preparations either contain a single active ingredient or a combination of ingredients, e.g., an anesthetic and antidepressant. Compounded topical formulations may be used in conjunction with oral medications and other treatments.

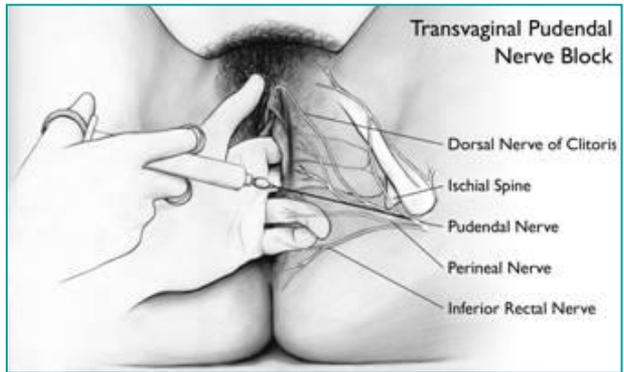
Physical Therapy

Some women with vulvodynia have pelvic floor muscle weakness or spasm. In addition to evaluating pelvic floor muscles internally, a physical therapist should assess joints, muscles and nerves in the lower half of the body to determine if they play a role in your vulvar pain. Treatment may include exercises and manual therapies, such as massage, soft-tissue work and joint mobilization. Modalities such as ultrasound, electrical stimulation and applying cold/heat may also be helpful.

In addition, rehabilitation of the pelvic floor muscles may include insertion of a vaginal sensor and the use of a biofeedback machine. The machine provides visual feedback on the strength of pelvic floor muscles while you perform exercises to normalize their function. This type of biofeedback is conducted by specially trained providers and some physical therapists.

Nerve Blocks

The pudendal nerve carries pain signals from the vulva to the spinal cord. A nerve block is an injection of anesthetic, often combined with an anti-inflammatory, that interferes with pain transmission. In many cases, a series



of injections, spaced days or weeks apart, is administered intravaginally (pictured above) or in the epidural space in the lower back (same as during childbirth). Most women experience short-term pain relief with this procedure, while some experience long-term relief. A recent study found that women with vulvodynia who underwent a series of multi-level nerve blocks (vulvar, pudendal and spinal) experienced sustained pain relief.

Neurostimulation and Spinal Infusion Pump

In severe cases, when more conservative forms of treatment have not worked, neurostimulation or implantation of a spinal infusion pump may be recommended. Neurostimulation involves the implantation of an electronic device that delivers low voltage electrical stimulation to the spinal cord, or a targeted peripheral nerve, with the intent of substituting a tingling sensation for pain. Spinal infusion pumps continually administer very small amounts of medication to the spinal cord and nerve roots. For information, visit www.nva.org/shg2.

Surgery for Women with Provoked Vestibulodynia

Some women with PVD are appropriate candidates for surgical treatment, whereas women with generalized vulvodynia are not. The key to positive surgical outcome is careful patient selection.

The most common surgical procedure for women with PVD is a vestibulectomy with vaginal advancement. This involves the removal of a portion (or all) of the vestibule, including the hymen, and then covering the excised area with vaginal tissue. Some doctors perform a modified vestibulectomy, in which only the superficial painful tissue is removed and there is no vaginal advancement. Most published results are based on vestibulectomy with vaginal advancement. It is difficult to compare the results of surgical studies because they do not use the same outcome measures and the length of the follow-up period differs. Overall success rates for both procedures range from 60 to 93 percent. After surgery,

physical therapy and the use of dilators may be recommended to help eliminate remaining pelvic floor muscle abnormalities. (To view diagrams of the two procedures, please visit www.nva.org/vestibulectomy and www.nva.org/shg3.)

Additional Treatments

The treatments described above are the most common ones, but your provider may recommend another approach that is specific to your case. Other treatments that have been used include topical steroids, capsaicin cream and injections of anesthetic, steroid, or Botox. There is a lack of controlled research on the efficacy of these treatments, however. For more details, read the Vulvodynia Guideline at www.nva.org/Haefner.

Complementary or Alternative Medicine

Women with vulvodynia, as with any type of chronic pain, may benefit from using alternative therapies in conjunction with traditional medical treatments. There are many complementary therapies, such as acupuncture, massage therapy, relaxation techniques and cognitive behavior therapy. To learn about complementary treatments, please visit the National Center for Complementary and Alternative Medicine's website, www.nccam.nih.gov.

Managing Breakthrough Pain

Sometimes a pain flare escalates suddenly and breaks through your regular pain management regimen. In addition to a long-term treatment strategy, you should discuss with your provider, in advance, how to handle a pain flare. In many cases, he/she will write a prescription for a short-acting narcotic, such as hydrocodone or oxycodone. To learn more about the management of breakthrough pain, please visit www.nva.org/shg4.

Looking Ahead

Keep in mind that research on vulvodynia is ongoing, with current studies investigating its causes and treatments. To view a list of studies in need of participants, please visit the NVA's website at www.nva.org/participate.

I didn't know anything about vulvodynia when I was diagnosed. I am very relieved to know that there are so many treatment options.

- Samantha Harrison, Columbus, Ohio

Self-Help Strategies for Vulvar Pain

While you are seeking effective treatment for vulvar pain, you also need coping measures to relieve symptoms and prevent further irritation. Even when your symptoms are under control, you should follow the guidelines below as a preventive strategy.

Clothing and Laundry

- Wear all-white cotton underwear, skirts or loose-fitting pants.
- Wear thigh-high or knee-high hose instead of pantyhose.
- Remove wet bathing suits and exercise clothing promptly.
- Use dermatologically-approved detergent such as Purex.
- Double-rinse your underwear and other clothing that touches the vulva.
- Do not use fabric softener on undergarments.

Hygiene

- Use soft, white, unscented toilet paper.
- Avoid getting shampoo on the vulva.
- Do not use bubble bath, douches, or any perfumed creams or soaps.
- Wash the vulva with cool to lukewarm water only.
- Urinate before bladder is full and rinse the vulva with water afterwards.
- Prevent constipation by adding fiber to your diet and drinking plenty of liquids, especially water, throughout the day.
- Use 100 percent cotton menstrual pads and tampons.

Sexual Intercourse

- Use a water-soluble lubricant that does not contain propylene glycol.
- Do not use contraceptive creams or spermicides.
- Ask your provider to prescribe a topical anesthetic, e.g., lidocaine, to be applied 5 to 10 minutes before intercourse.
- Wrap ice or a frozen gel pack in a thin towel and apply for 10 to 15 minutes after intercourse.
- Urinate and rinse the vulva with cool water after intercourse.

Physical Activities

- Avoid exercises that put direct pressure on the vulva, e.g., bike riding.
- Limit intense exercises that create a lot of friction in the vulvar area.
- Wrap ice or a frozen gel pack in thin towel and apply after exercise.
- Learn stretching and relaxation exercises.
- Do not swim in highly chlorinated pools or use hot tubs.

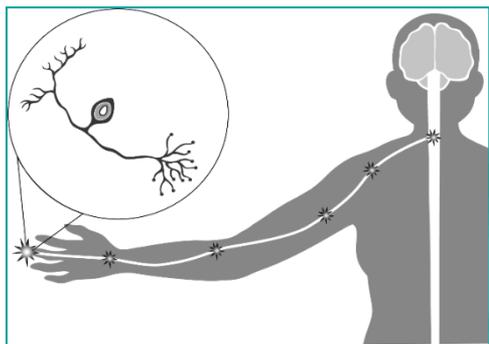
Everyday Living

- Try using a specialized cushion or foam donut for long periods of sitting.
- For temporary relief, wrap ice or a frozen gel pack in a thin towel and apply for 15 minutes or take a sitz bath with lukewarm or cool water.
- If you primarily sit at work all day, intersperse periods of standing.
- Learn some relaxation techniques to use during the day. (See Relaxation and Stress Reduction Workbook, details on page 32.)

Section III: Understanding Chronic Pain

Although 25 percent of adult Americans suffer from a chronic pain condition, patients in pain are a neglected and under-treated group compared to patients suffering from other medical disorders. Annually, about 50 percent of Americans seek medical care for pain, making it the most common reason for consulting a physician. This surge in pain patients has finally led the health care community to recognize pain as the fifth vital sign, in addition to temperature, heart rate, blood pressure and respiratory rate. Having a basic understanding of the body's pain mechanisms can help you to describe your pain symptoms and discuss treatment options with your health care provider.

How We Feel Pain



Pain is a complex physiological process. As seen in the diagram on the left, when pain receptors are triggered, specialized nerves carry the pain “message” to the spinal cord and the brain. Once the brain receives and interprets the pain message, it coordinates an appropriate response. The brain can send a signal back to the spinal cord and nerves to increase or decrease the severity

of pain. For example, the brain may signal the release of natural painkillers known as endorphins. Alternatively, the brain may direct the release of chemical messengers or hormones that can intensify pain and/or stimulate the immune system to respond to an injury.

When Pain Becomes Chronic

In general, pain is divided into two categories, acute and chronic. In an acute pain episode, pain receptors transmit information about an injury to the spinal cord and brain, leading you to protect the injured area. Examples of acute pain are burning yourself on the stove or stubbing your toe. This type of pain resolves once the injury heals. Sometimes, however, your body heals, but your brain continues to perceive the pain. For an unknown reason, the acute pain becomes chronic.

The majority of physicians define pain as *chronic* if it persists for at least three to six months, while others define it as pain that endures beyond the expected healing time. In some cases, chronic pain is due to an ongoing medical condition, such as arthritis or cancer, but in many cases, it does not have an identifiable cause. Chronic pain can last for months or years, be constant or intermittent, and vary in severity over time.

Coping with Chronic Pain

Chronic pain may lead to changes in your life, sometimes making it difficult to work, sleep, socialize and perform other daily activities. It can also strain relationships or make you feel depressed and/or anxious. The good news is that there are medications and other treatments that can provide some pain relief. Learning how to control chronic pain is just as important for your emotional well-being as it is for your physical health. In this section, we will suggest some strategies for managing pain and its consequences.

Acknowledge Your Feelings and Regain Control of Your Life

At some point, you may feel sad, angry and/or anxious about the impact of vulvodynia on your quality of life. These are common feelings among women with vulvodynia. Some women find it helpful to discuss their feelings with a family member, friend or health care provider. Some women find that expressing their feelings in a written journal is helpful.

You should try not to let negative emotions overwhelm you. In the beginning, it is common for women with vulvodynia to feel that the pain has taken over their life. To overcome feeling helpless and regain control, accept that you have pain and take ownership of it. This involves being realistic about what you can or cannot do and not allowing your physical limitations to define who you are. It makes a big difference when you view the glass as half full rather than half empty. Millions of people have chronic pain and many lead happy and fulfilling lives, while others do not. What makes the difference is deciding to focus on your strengths and enjoy the activities that you are able to do, instead of dwelling on what you cannot do. *Simply put, you can have a rewarding life in spite of chronic pain.* An important part of this process is developing a positive attitude, which takes time and practice. Substitute negative thoughts such as, “I’m never going to feel better,” with “I’m going to do everything I can to feel better.” Negative thoughts cause anxiety, which intensifies pain. Maintaining a positive attitude takes the focus off your pain and keeps anxiety in check, which helps you feel better both emotionally and physically.

Adopt a Healthy Lifestyle

A nutritious diet, adequate sleep and daily exercise are critical for everyone, but certainly for people with chronic pain. Eat a balanced diet with lots of vegetables and fruits, limit simple carbohydrates and unhealthy fats, and drink six to eight full glasses of water daily. If you need guidance on healthy eating, see a nutritionist. Since sleep, mood and pain are closely linked, it’s important to get enough restorative sleep. If you’re not sleeping seven or eight hours each night, or have difficulty falling asleep because of pain, talk to your provider. Although many people with chronic pain hesitate to exercise, unused muscles usually cause more pain than toned, flexible ones. Research shows that aerobic exercise boosts the body’s natural painkillers and enhances mood. Under the guidance of a health care provider, choose

an appropriate exercise program. A good rule is to “start low and go slow,” e.g., start with a 10-minute walk and gradually increase the duration, frequency and intensity. Everyday stress may also worsen pain, but you can learn to control it with meditation or relaxation techniques, such as deep breathing and yoga. Discuss stress-relieving strategies with your provider or a psychologist.

Be an Active Participant in Your Care

You are an important member of your health care team. Educate yourself about your condition and don't hesitate to ask questions. Work with your provider to achieve your goals.

Try a Multi-Modal Treatment Approach

There may not be simple solutions to chronic pain, but that doesn't mean improvement isn't possible. Many treatment options are available and you can try a combination of treatments to lessen your pain. You may want to consider a regimen that includes both medical and complementary strategies. You may have to try many treatments before finding the ones that work best for you. Many women find that combining medication, physical therapy and a complementary treatment, such as acupuncture or massage, provides the greatest relief. Psychological counseling should also be considered if you feel anxious or depressed, or simply want to discuss the impact of vulvodynia on your life.

Spend Your Energy Wisely

Pain can affect your energy level or impose other limitations. Some women find it helpful to alternate rest and activity throughout the day because “overdoing it” can lead to increased pain. On the other hand, you don't want to fall into a cycle of inactivity that causes muscle tightness and weakness, which can contribute to pain. You need to determine the right balance of activity and rest for your physical and mental well-being.

Managing a Flare-Up

By keeping a pain diary, you can learn which activities intensify your pain and then keep them to a minimum. Sometimes you can't avoid certain activities, however, or a spontaneous flare-up occurs. Discuss with your provider, in advance, how to manage a flare-up. These situations often require taking additional medication and using self-help measures, such as a sitz bath. Specific relaxation techniques or engaging in activities you find relaxing, e.g., listening to music, may also help.

Help Others

As you seek ways to manage your pain, reach out to other women in need. Sharing what you've experienced may be of great benefit to other women and helping others can make you feel good about yourself.

Section IV: Quality of Life Issues

Overcoming Challenges in Your Intimate Relationship

Chronic pain, and especially vulvodynia, tends to interfere with your sexual relationship. It may affect your ability to engage in sexual intercourse, but that doesn't mean your intimate relationship has to be over. In fact, avoiding all sexual activity can be self-defeating if it leads to a loss of desire in either partner. It is possible to create a satisfying intimate relationship with your partner even when you suffer from vulvodynia.

Start Talking About It

Communication is key to a healthy sex life for all couples, but many people are uncomfortable having conversations about sex and assume that their partner already knows their preferences. How can you know what your partner likes without asking? Talking becomes even more important when your intimate life is challenged by a chronic pain condition. Discussing your concerns and fears, or what is painful or pleasurable, can lay the groundwork for a mutually satisfying sexual relationship. At first, these conversations may make you uncomfortable, but it will get easier with practice. Here are some suggestions for facilitating a productive conversation about sex.

- **Timing and Location**

You should not spring this type of conversation on your partner. Decide upon a time and place. It is unwise to have this conversation while intimate or during a romantic date.

- **Write Down Your Feelings**

Writing down what you want to say beforehand is a good way to clarify what you are feeling. It can also help you practice the best way to express your feelings and thoughts.

- **Create Safety and Show Respect**

In order to disclose such personal feelings, both of you need to feel safe. Since the conversation will likely involve a discussion of novel intimate activities, you should agree not to embarrass or laugh at each other. If he/she takes the risk of exposing private sexual desires, be respectful and consider that kind of sharing a compliment.

- **Listen Without Interrupting**

Learning not to interrupt is essential for intimate communication. You and your partner must agree to not interrupt each other. If you make a mistake, apologize and focus on listening until your partner is finished speaking. If it is difficult for either of you to stop interrupting, choose a random object and give it to the partner who is speaking. When finished, the object is handed to the other partner. While your partner is speaking, try to jot down points you want to respond to.

- **Make “I” Statements**

Try to avoid telling your partner how he/she feels or thinks. Talk about *your* feelings, by starting sentences with the word “I.” For example, say, “I feel uncomfortable when you...” rather than, “You make me uncomfortable when you...” By speaking in the first person, it doesn't sound like you're blaming your partner.

- **Be Specific and Ask Questions**

Try to avoid making sweeping statements such as, “You always do that,” or, “I'll never be able to do that.” Be as specific as you can in your descriptions. If your partner makes general statements, request clarification and ask questions to improve your understanding.

- **Agree on Confidentiality**

Since discussing your sexuality is such a private matter, the two of you should agree on confidentiality limits of your conversation. For example, is it okay for your partner to share this conversation with a close relative or best friend? Respect confidentiality.

- **Time-Out**

Before you begin, agree that either of you can ask for a 20 to 30 minute intermission or to end the conversation.

- **Schedule Another Time to Talk**

Conversations about sexual intimacy should be an ongoing process. It is unlikely that you will completely resolve an issue, or even cover all aspects of it, in one sitting. Before you end your conversation, the two of you should agree to continue the discussion at a later date.

Now that we've covered some basic communication ground rules, here are some issues you may choose to discuss with your partner.

- **Satisfaction with Intimate Relationship**

How satisfied were both of you with your sexual relationship prior to your vulvodynia? Were there conflicts that predated your vulvodynia or did both of you have a high level of satisfaction with your intimate relationship? How has vulvodynia changed your sex life? For example, have you become fearful that sexual activity will increase your pain? Is the pain causing you to avoid intimacy? Does your partner fear hurting you during sexual activity or feel rejected because you don't initiate sex? Have you become the sole initiator because you are the one in pain? How do these changes make you and your partner feel?

- **Painful or Pleasurable**

It is important for your partner to know which vulvar areas elicit pain when touched. You can identify them yourself or your partner can accompany you to a medical appointment and your doctor can identify

the areas. You should also tell your partner which parts of your body give you pleasure when touched. In addition to location, which sexual activities give you pain or pleasure? Which sexual positions do you find most comfortable?

- **What Does Your Partner Enjoy?**

A simple aid to help you begin this conversation is a foreplay map (www.nva.org/shg5). In this exercise, you label body parts in the order you prefer them to be touched. You also label body parts in the order you think your partner likes to be touched. Your partner does the same exercise and then you compare results.

- **Redefine What Intimacy Means**

People vary a great deal in their sexual attitudes and practices, so it is important to remember that “normal” is whatever gives you and your partner pleasure. Intimacy doesn’t necessarily equal intercourse. You should not feel obligated to have penetrative sexual intercourse if it causes pain, because in addition to the immediate discomfort, you may learn to permanently associate sex and pain. There are a variety of non-penetrative sexual activities that provide mutual pleasure and help to maintain intimacy. Books such as Dodson’s *Sex for One*, and Klein and Robbins’ *Let Me Count the Ways: Discovering Great Sex Without Intercourse*, discuss these alternatives. (See Recommended Reading on page 32.) Your partner may be more open-minded than you think and trying new sexual practices can add some excitement to your relationship.

- **Plan Ahead for Pain Flares**

It is common for flare-ups to occur, leading to extended periods of time when sexual intercourse is out of the question. It’s very helpful for you and your partner to develop a plan for dealing with this situation. You can agree to try other types of sexual closeness or non-sexual ways of expressing intimacy during flare-ups. If you discuss how to handle this situation beforehand, your partner is more likely to understand instead of feeling rejected.

- **Other Gestures of Affection**

Both you and your partner can compose a list of non-sexual gestures that make you feel loved and valued. For example, your list might include having your partner accompany you to medical visits, hold your hand, or give you a massage. After you have composed your lists, exchange them. Both of you should try to do one item from your partner’s list each day. Small gestures can go a long way toward fostering affection and closeness in your relationship.

Keeping Sexual Intimacy Alive

Here are more suggestions for maintaining intimacy in your relationship.

- **Schedule a Time for Intimacy**

Many couples believe that sexual intimacy should occur without planning. As a relationship progresses, even without vulvodynia, spontaneity often dissipates due to work responsibilities, children and other commitments. Most couples find that they need to schedule time for closeness. Plan some relaxed time together that will enable you to slowly begin your rediscovery process.

- **Keep Track of Sexual Thoughts**

If vulvodynia has lessened your desire, try keeping track of your sexual thoughts in a diary. Every day for several weeks, when you have a sexual thought or feeling, no matter how fleeting, write it down. Note the time of day, whether you are alone or with someone, and what you did about it. Sometimes just keeping track of sexual thoughts increases desire.

- **Exploration and Foreplay**

Create a relaxing environment by lighting candles or playing soft music. If you haven't been intimate for a long time, it's a good idea to set some limits. For example, you can agree to engage in a touching session that avoids the vulvovaginal area. Your goal is to feel relaxed and simply enjoy sensual pleasure by exploring each other's bodies. This session may include petting, caressing, stroking, kissing and massaging. Both of you should focus on what feels pleasurable and communicate what you feel to each other.

- **Sexual Intercourse**

If you decide to engage in penetrative intercourse, take it slowly. You can start by using a finger to gauge how it will feel. Choose a time of day when you experience the least amount of pain. Use a generous amount of lubrication to eliminate friction and make sure you are fully aroused prior to penetration. Choose a position that reduces pressure on the sensitive vulvar areas and limit thrusting time. If helpful, you can support yourself with a pillow. The use of a topical anesthetic, e.g., lidocaine, prior to intercourse helps to relieve the discomfort of penetration. You should let your partner know what causes pain and suggest other ways to touch you that aren't painful.

- **Reintroduce Spontaneity**

Once your pain is controlled, consider offering your partner a 'window of wellness' period during which he/she can feel comfortable initiating intimacy. This may help to revive the spontaneity that has been lost and lets your partner know that you haven't lost interest.

When to Seek Counseling

For some couples, relationship conflict predates the development of vulvodynia, or, in some cases, the condition impacts a relationship so dramatically that one or both partners feel the need to consult a therapist. Other couples may cope quite well, but still choose to seek the advice of a therapist. You and your partner should discuss whether visiting a couples and/or sex therapist would be of benefit. Remember that you are not the first couple to face this challenge and it's okay to ask for help.

To find a knowledgeable therapist or counselor, ask your provider for a referral. You can also check the health care provider list on NVA's website at www.nva.org (click on the US map on our home page) or visit the websites of professional organizations, such as the American Association of Sexuality Educators, Counselors and Therapists (www.aasect.org) or the American Association of Marriage and Family Therapists (www.aamft.org). Before making an appointment, contact a few different therapists and ask about their experience dealing with families or couples facing chronic illness and/or sexual intimacy issues related to chronic pain.

Special Issues for Single Women

If you are not in a relationship, you may have reservations about starting one or concerns about finding a partner who will understand your limitations. Feeling that way is understandable, but it shouldn't stop you from dating if you want to do so. Mature compassionate partners, who can handle a relationship with someone who has vulvodynia, do exist. Vulvodynia is one aspect of your life, but does not define you. Many women with vulvodynia have found loving partners and enjoy satisfying sex lives. If you decide to date, or are in a new relationship, here are a few suggestions.

Dating: Timing and Location. If you're nervous about the unknown aspects of a date, set it up yourself. If you have difficulty sitting, choose a restaurant that you know has comfortable chairs. If you tend to feel worse late in the day, suggest a lunch date. If mild activity makes you feel better, meet at a park so you can walk.

When to Bring it Up. You're not obligated to disclose your medical history to someone on your first few dates. After you have developed mutual respect and feel comfortable enough to be intimate, you can choose an appropriate time to discuss your condition. Most importantly, don't wait until you are in the midst of a sexual encounter. When you decide to disclose your condition to someone you are dating, see the *Start Talking About It* section on pages 20 and 21.

The NVA has identified support groups and email contacts for women who want to be in contact with someone else who has vulvodynia. To find out more, go to www.nva.org/support.

Family Life Issues

Vulvodynia sometimes requires lifestyle changes that are difficult to accept. Depending on the severity of your pain, you may experience difficulty sitting for long periods, which can affect work and family responsibilities.

Families have to adjust their expectations of what you can do during times when your pain is severe. Acknowledge your feelings of loss and then try to focus on the activities that you can still do with your family. Remember, even if your pain is unrelenting today, with medical care and perseverance, it is likely to improve.

Vulvodynia may affect the following areas of family life:

- **Household Responsibilities**

Families develop a pattern for handling household tasks. When one member develops chronic pain, this pattern may be disrupted. Time and energy spent seeking medical treatment for vulvodynia, or the side effects of medication, lessen the time you have to devote to household chores and responsibilities. It is likely that others in the household will have to carry the extra load while you find a way to manage your condition. Discuss hiring outside help or asking relatives to pitch in occasionally.

- **Parenting**

Parenting roles are affected when one parent suffers from a chronic pain condition. Whether you work at home or at an office (or not at all), dealing with the challenges of raising children are understandably more difficult when you are in pain. If possible, you can ask family members or close friends to assist with child care duties during times of heightened pain. Consider hiring someone to help with the children during the week or enroll your children in after-school or daycare programs.

- **Children's Concerns**

Your children will likely experience some feelings and concerns about your condition and associated changes. Even very young children notice when a parent isn't feeling well, lacks patience or cannot sit for long periods of time. Whether you decide to disclose your condition to your children or not, they will know that something is wrong. If you don't talk to them, you run the risk that they will arrive at their own conclusions, e.g., they may think that you have a life-threatening

illness. Of course, the amount of information a child needs depends on his/her age and ability to understand. Be honest and let your children know how they will be affected.

Here are some practical suggestions for talking with your children:

- Give a general description of your condition.
- Emphasize that the pain is not their fault and they can't catch it.
- Assure them that you're working with the doctor to feel better.
- Let your children know that pain can be unpredictable, i.e., sometimes you may seem fine, but other times you may not be able to participate in certain activities.
- Talk to them about any scheduling changes you need to make while you seek care. Tell them who will take care of their needs, such as picking them up from school.

- **Career Changes**

Fortunately, many women with vulvodynia are able to continue working, although some have to make adjustments. Although discussing vulvodynia with your employer may be uncomfortable, sometimes it is necessary. The goal is to agree upon a plan that allows you to manage your pain and care for yourself, while maintaining financial security and adequate health insurance. If additional home and childcare responsibilities are affecting your partner's work, your partner may also need to speak with his/her employer.

If your pain is severe, you may not be able to concentrate, sit for long periods, travel and/or socialize at work functions. In this case, you may have to take a temporary leave of absence or resign from your position. (If you can no longer work, download the NVA's guide, *How to Apply for Disability Benefits*, at www.nva.org/disability.)

It is likely to take some time for your family to adjust to the changes. If you notice that your partner or child is emotionally distressed, you may want to consult a family therapist who specializes in the impact of chronic illness on families.

Remember, even if your pain is unrelenting now, persevere in seeking treatment and you will feel much better in the future.

Section V: Getting the Most Out of Your Medical Care

Everyone knows that our health care system is far from perfect. One common complaint is that many physicians only spend five to ten minutes with their patients. In order to maximize the value of these visits, you have to change your mindset to that of a *medical consumer*.

How to Find a Health Care Provider

Finding a knowledgeable, caring medical provider to work with you and your health care team is critical. If your current provider isn't experienced, ask for a referral to a specialist. The NVA also maintains a national database of health care professionals who treat vulvar pain disorders. To access our referral list, go to www.nva.org, click on the US map and enter your zip code. If there isn't a vulvodynia expert in your area and you're unable to travel, ask your provider if he/she is willing to learn about the condition and its treatment. You can refer him/her to our provider tutorial at www.nva.org/ce.

Educate Yourself

It is essential that you learn as much as you can about vulvodynia. The NVA has more than 60 issues of its newsletter online, featuring articles written by vulvodynia experts. These issues of *NVA News*, plus our online patient tutorial, provide detailed information about different treatments. There are also some excellent books authored by vulvodynia experts. (See Recommended Reading, page 32.)

How to Communicate Effectively with Your Health Care Provider

To receive the quality care you need, you should communicate with your health care provider on a regular basis. In this section, we will offer some suggestions for establishing a productive relationship with him/her.

Prepare for Your Appointment

It is important to take some time to prepare for each medical appointment. Before your appointment:

- Transfer relevant medical records, films and lab results to your new provider, or fax the information to the office several days before your appointment.
- Request forms that the doctor needs you to complete in advance, so you won't have to rush to complete them in the waiting room.
- Consider keeping a pain diary for several weeks or months prior to your appointment and/or complete the International Pelvic Pain Society (IPPS) questionnaire. You can download a pain diary at <http://www.nva.org/paindiary> and the IPPS questionnaire at

<http://www.nva.org/shg1>. In addition to recording your symptoms prior to your first appointment, use the diary to track your progress in between appointments.

- Write down questions and bring them to your appointment.
- Consider asking a family member or friend to accompany you to the appointment to help you recall the provider's instructions, especially if it's the first visit. If your provider doesn't mind, you can also record the session.

During your appointment, remember to:

- Be concise, but give details. Refer to your written questions.
- Take notes.
- Ask for clarification if you don't understand something.
- Let your provider know if you need more time to discuss your concerns. If he/she can't dedicate more time during your visit, schedule a follow-up appointment or phone call, or ask if you can speak further with the nurse or physician assistant.
- Ask why certain lab work or tests are necessary and make sure the provider contacts you to explain the results.
- Ask your provider about any office policies or procedures. For example, how should you handle prescription refill requests and referrals? If opioids are prescribed, some offices require a written agreement and routine drug screening. Knowing office procedures can prevent future misunderstandings.
- Ask your health care providers to communicate with each other. Because people with chronic pain are often under the care of multiple specialists, it is important for the medical team to collaborate. Make sure that a summary of each visit is sent to other members of your health care team.

Issues to Address During Your Appointment

Chronic pain is complex and can affect you in many ways. Your ability to work, sleep, engage in sexual intercourse and participate in social activities may be affected. Since your provider cannot see the intensity of your pain, it is up to you to describe your symptoms and how they affect your life. You also have to reveal your complete medical history, which includes a list of all your medical conditions and medications (prescription and non-prescription).

You should share the following information with your provider:

Pain Location

Where is your pain? Is it localized or generalized? Is it superficial or does it feel deep and penetrating? Does it travel or radiate? Do you experience pain in other areas of your body?

Pain Quality

What does the pain feel like? Women with vulvodynia typically use the following words to describe their pain:

Hot	Lacerating	Shooting	Sharp
Burning	Stabbing	Throbbing	Pinching
Scalding	Tight	Tender/Sore	Cutting
Searing	Stretching	Knife-like	Raw

Pain Intensity

How severe is your pain? How would you rate your pain on a ten-point scale, where 0 indicates no pain and 10 indicates severe pain?

No Pain

Moderate

Severe Pain

0

5

10

Pain Pattern, Duration & Frequency

Is your pain constant or intermittent? Does it start gradually or become intense suddenly? Does it increase with certain activities?

Moderating Factors and Associated Symptoms

Which activities or treatments help to relieve (or increase) your pain? Is your usual pain or pain flare accompanied by other symptoms, such as fatigue, fever, weakness or numbness?

Emotional, Social and Sexual Effects

How does the pain affect your daily functioning and emotional well-being? Are you unable to sit or walk because of your pain? How does the pain affect your mood, relationships and sexual health?

If you have vulvodynia, it is common to see two or three specialists from different medical disciplines. It is important for them to share your test results and treatment information with each other.

Seeking a Second Opinion or Changing Doctors

Sometimes it is very important to seek a second opinion. First, if you have doubts about the accuracy of your diagnosis, you should always seek a second opinion. Doctors differ in their approaches. Some start with the most conservative treatment, e.g., eliminate all possible vulvar irritants, while others may prescribe oral or topical medication right away, in addition to having you eliminate irritants.

Some gynecologists are either not experienced in the treatment of pain or underestimate its impact on your quality of life. It is essential to find a doctor committed to treating your pain, so some women choose to see both a gynecologist and a pain management specialist.

It is also possible that you are not satisfied with your health care provider's level of care. If you experience one or more of the following, consider making a change:

- Your provider tells you that your pain is “all in your head” or that there is nothing more he/she can do for you.
- You have a difficult time getting timely appointments.
- Your provider is unwilling to work with other members of your health care team.
- Your provider is dismissive of your concerns or has a poor bedside manner.
- You are spending more time with the nurses and office staff than your provider.
- Your phone calls and questions go unanswered.
- You find yourself repeating basic information at each appointment.

When I contacted the NVA, I immediately received a health care referral list. The doctor I chose was very thorough, explained that I had generalized vulvodynia and prescribed medication. Three months later, my pain was 50% less.

- Stephanie Rosen, San Francisco, California

Section VI: Advice from Women with Vulvodynia

A University of Alberta study investigated the long-term effects of vulvodynia on women's lives. Among the survey's questions, women were asked, "If you were asked to give advice to a young woman who has just been told she has vulvodynia, what would you say?" Their answers are below.

"Be assertive, persevere, have hope."

Many women said that it was important to persevere in seeking pain relief. They recommend being assertive with medical personnel when necessary, e.g., when you urgently need an appointment or a doctor only spends 10 minutes with you. The majority of women emphasized that you should never give up hope, no matter how frustrated you feel.

"Discuss with your provider whether a new treatment is right for you."

Another common theme was the importance of developing a collaborative relationship with a health care provider. Women advised finding a provider who respects your knowledge about your condition, answers your questions and is willing to discuss options with you. Some emphasized the need to establish a balance between relying on your own judgment and trusting your provider's medical expertise.

"Communicate with other women who have vulvodynia so you don't feel isolated."

Many women identified 'feeling alone' as one of the greatest threats to their emotional well-being. They suggested speaking with other sufferers to lessen the isolation and share medical information.

"Learn as much as you can."

The survey respondents said that they learned a lot about vulvodynia treatment options by reading back issues of the NVA newsletter (available at www.nva.org/newsletter). They thought it was essential to understand different treatments to intelligently discuss your options with your doctor.

The NVA e-mails the latest information on vulvodynia treatment as well as recent research abstracts on chronic vulvar pain.

Recommended Reading

Ellen Catalano and Kimerin Hardin, *The Chronic Pain Control Workbook: A Step-By-Step Guide for Coping with and Overcoming Pain*, 1996.

Deborah Coady and Nancy Fish, *Healing Painful Sex: A Woman's Guide to Confronting, Diagnosing, and Treating Sexual Pain*, 2011.

Martha Davis, Elizabeth Eshelman and Matthew McKay, *The Relaxation and Stress Reduction Workbook*, 2019.

Betty Dodson, *Sex for One: The Joy of Selfloving*, 1996.

Howard Glazer and Gae Rodke, *The Vulvodynia Survival Guide: How to Overcome Painful Vaginal Symptoms & Enjoy an Active Lifestyle*, 2002.

Andrew Goldstein, Caroline Pukall and Irwin Goldstein, *Female Sexual Pain Disorders: Evaluation and Management*, 2020.

Andrew Goldstein, Caroline Pukall, Irwin Goldstein and Jill Krapf, *When Sex Hurts: Understanding and Healing Pelvic Pain*, 2023.

Isa Herrera, *Ending Female Pain, A Woman's Manual, Expanded 2nd Edition: The Ultimate Self-Help Guide for Women Suffering from Chronic Pelvic and Sexual Pain*, 2014.

Marty Klein and Riki Robbins, *Let Me Count the Ways: Discovering Great Sex Without Intercourse*, 1999.

Robert Moldwin, *The Interstitial Cystitis Survival Guide: Your Guide to the Latest Treatment Options and Coping Strategies*, 2000.

Christiane Northrup, *Women's Bodies, Women's Wisdom: Creating Physical and Emotional Health and Healing*, 2020.

Judith Reichman, *Relax, This Won't Hurt: Painless Answers to Women's Most Pressing Health Questions*, 2010.

Jennifer Schneider, *Living with Chronic Pain, Second Edition: The Complete Health Guide to the Causes and Treatment of Chronic Pain*, 2009.

Amy Stein, *Heal Pelvic Pain: The Proven Stretching, Strengthening, and Nutrition Program for Relieving Pain, Incontinence, IBS, and Other Symptoms Without Surgery*, 2008.

Elizabeth Stewart and Paula Spencer, *The V Book: A Doctor's Guide to Complete Vulvovaginal Health*, 2002.

NVA Educational Booklets

The NVA has created three additional educational booklets that members can view at www.nva.org/shg. To obtain a printed copy, please contact the NVA by phone (301-299-0775) or e-mail (admin@nva.org).

Vulvodynia, Pregnancy and Conception

The NVA's pregnancy booklet is the first comprehensive resource on the subject for women with vulvodynia who are pregnant or want to become pregnant. It covers material from conception through the postpartum period, dealing with topics such as alleviating vulvar pain during pregnancy and minimizing trauma to the vulva during childbirth. The booklet also discusses alternative methods of conception and childbirth options.

My Partner Has Vulvodynia – What Do I Need to Know?

After reading this brief guide, partners should have a better understanding of vulvodynia and the challenges of living with it. In addition to suggesting how partners can be supportive, it discusses the impact of vulvodynia on relationships and ways to keep sexual intimacy alive.

How to Apply for Disability Benefits

This guide is intended for women who cannot continue to work and are seeking disability benefits from the Social Security Administration. It provides step-by-step guidance that will help vulvodynia sufferers compile and submit a successful claim. Facts and figures on vulvodynia, and a list of additional resources are included.

What the NVA Can Offer You

Founded in 1994 by five patients, the NVA's mission is to help improve the health and quality of life of women suffering from vulvodynia. We do this in several ways. First, NVA educates patients via its website, brochures, patient guides, newsletters and support network. For health care providers, we created an accredited continuing education online tutorial, which has been viewed by 52,000 medical professionals. Many more doctors are knowledgeable about vulvodynia today, because of this tutorial and our awareness campaign. Lastly, we award research grants each year for studies on the causes and treatment of vulvodynia. If you would like to join the NVA listserve, visit www.nva.org/join.

How You Can Make A Difference

Researchers have found that up to 12 percent of US women suffer from vulvodynia at some point in their lives. By combining our voices and skills, the NVA is making a significant impact, changing the future for ourselves and the women who will come after us. Please donate to the NVA, volunteer your time or be a source of support to other women when you are feeling better. To learn more, you can visit www.nva.org/make-a-difference.



FOR MORE INFORMATION:

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