

*"I have Vulvodynia-
What do I
Need to know?"*

**A Self-Help Guide for Women
Diagnosed with Vulvodynia**

Presented by the
National Vulvodynia Association
through an unrestricted educational grant from
Purdue Pharma, L.P.

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Acknowledgement: With special thanks to NVA's Christin Veasley for developing this guide, to NVA medical advisory board member Stanley C. Marinoff, MD, for his guidance and expertise, and to Lyn Fletcher for designing the cover. This guide was written for every woman with vulvodynia who, at some point in her life, thought she was suffering alone. *Phyllis Mate, co-founder of NVA*

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 first patient self-help guide published by the National Vulvodynia Association. We developed the guide primarily for recently diagnosed women, but it contains useful information for any woman who suffers from vulvodynia. In addition to helping you understand the condition and its treatments, we hope it will help you improve your quality of life. Before we get started, there are several important points to keep in mind as you read through this guide.

First of all, the fact that you have received a diagnosis is actually a positive event. Because many members of the medical community are not familiar with the condition, the majority of women visit upwards of five health care providers before receiving an accurate diagnosis. Now that you have a name for your condition, you can focus your attention on getting better instead of trying to figure out what is wrong.

Second, each woman's experience with vulvodynia is unique and the severity of symptoms different women experience ranges from mild to incapacitating. Depending on where you are on this continuum, some of the information in this guide may or may not be applicable to you.

Most important to remember, individuals respond differently to medical treatment and no single treatment works equally well for all women with vulvodynia. However, you will find there are several treatments available. Sometimes progress may be slow and you may not notice changes day to day, but rather on a week-by-week or month-by-month basis. It's important to be patient and not give up hope.

Lastly, it is essential to your treatment that you communicate clearly and work cooperatively with your health care provider. Remember, you are a very important part of your health care team. You may find it helpful to write down notes as you read this guide and discuss any questions that come up with your provider.

So, with that in mind, let's begin!

VULVOVAGINAL ANATOMY

Most women don't know that the vulva and the vagina are two different organs. It is important to differentiate between them because they are not composed of similar tissue and exhibit different problems. This distinction is comparable to the mouth and lips. If you have chapped lips, you apply medication directly to your lips, not inside your mouth. Similarly, if you have a vulvar problem, inserting medication into the vagina will not remedy it. On the other hand, if you suffer from a vaginal yeast or bacterial infection, medication must be inserted directly into the vagina. Learning vulvovaginal anatomy is an important step towards improving your gynecological health care, because it will improve your understanding of vulvovaginal problems and enable you to communicate more effectively with your provider.

The vulva is located on the outside of the body.

The vulva is the external part of the female genitalia. The vulva protects a woman's sexual organs, urinary opening, vestibule and vagina and is the center of much of a woman's sexual response.¹

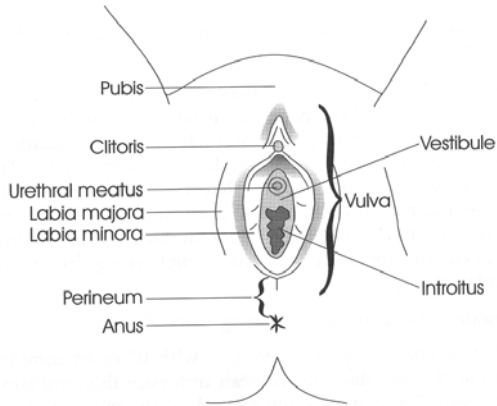


Diagram reproduced with permission from The Interstitial Cystitis Survival Guide by Robert Moldwin, MD, New Harbinger Publications, Inc. © 2000.

The outer and inner "lips" of the vulva are called the *labia majora* and *labia minora*. The *vestibule* surrounds the opening of the vagina, or *introitus*, and

the opening of the urethra, or *urethral meatus*. The *perineum* is the area that extends from beneath the vulva to the anus.

The vagina is located inside of the body.

The vagina is a passageway that begins at the *introitus* (vaginal opening) and ends inside the body at the *cervix*, the lowermost part of the uterus. The *urethra* sits directly anterior, or in front of the vagina and the *rectum* sits directly posterior, or behind the vagina. The width and length of the vagina vary from woman to woman.

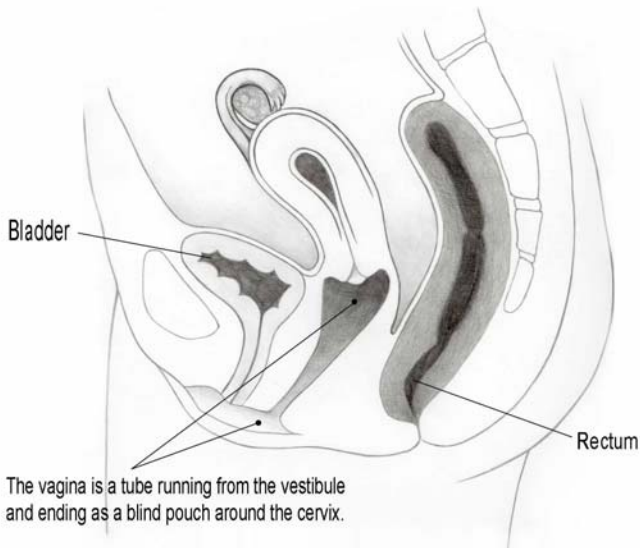


Diagram reproduced with permission from The V Book by Elizabeth G. Stewart, MD and Paula Spencer (illustrations by Dawn Danby and Paul Waggoner), Bantam Books © 2002.

The vagina is composed of a unique type of tissue that can expand and contract. It serves many functions: it is the passageway for menstrual flow; accommodates the penis during sexual intercourse; serves as the passageway during the birth of a child; allows access to the cervix for examination; and prevents certain harmful bacteria from entering the body.²

NORMAL AND ABNORMAL VULVOVAGINAL SYMPTOMS

Each woman's body is unique, and just as there are different body shapes, vulvas are not all the same. Vaginal secretions and odor vary as well. Sometimes it is difficult to know which characteristics are "normal" and which aren't. The following summary of vulvovaginal characteristics and some abnormal conditions may help you make this distinction.

Vulvar Skin Color and Texture

The labia majora appear similar to other skin surfaces on your body, are covered with pubic hair and contain protective fat that cushions during sexual intercourse. They contain hair follicles, sweat glands and other specialized glands. The labia minora are darker in color, varying from a deep pink to a brownish or reddish pink. They vary from thin, small flaps to thick, bumpy bulges.³ The edges of the labia often contain glands that make a pebbly appearance, like tiny pimples. The inner labia minora are smooth and moist.⁴ The skin of the vestibule is moist and pinkish, and sometimes appears quite red. The clitoris is covered by a hood that can be pulled back to expose the clitoris.

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

Discharge

Vaginal discharge is normal and the amount of discharge experienced will change over the course of the menstrual cycle and with hormonal status (an increase occurs mid-cycle during ovulation and just afterwards). The amount of discharge varies from woman to woman and it is important to become familiar with what is normal for you. Secretions are not actually made by the vagina, but come from several other sources including cells shed from the vaginal walls, mucus from the cervix, sweat and other specialized glands (Bartholin's and Skene's), just to name a few.⁵ If you take oral contraceptives, the amount of discharge experienced over the course of the month will not vary, because contraceptives provide your body with steady levels of estrogen and progesterone. Vaginal discharge is mildly acidic and its acidity functions to protect the vagina from infection. The color of discharge also changes over the course of the menstrual cycle, i.e., it may be milky white, clear or faintly yellow.

The most important thing to remember is that normal secretions do not itch, burn or irritate, nor do they smell like fish or ammonia. Abnormal discharge varies, but may include a change in the amount, smell, color (i.e., gray-white, yellow-white or yellow-green), and be blood-stained if inflammation is severe.⁶

Odor

The vulva contains a large number of sweat glands. Sweat allows heat to escape and is therefore a source of odor (similar to your underarms). This is normal, but if excessive, can be treated. Normal vaginal secretions may have an odor that changes over the course of the menstrual cycle, may not have any odor or may smell faintly like sour milk.⁷ Each woman has her own unique scent. Vaginitis is the most common reason for unpleasant and abnormal odor. Bacterial Vaginitis (BV) is the likeliest suspect, elevating the normally acidic pH of the vagina, causing an odor of ammonia, in mild cases, and dead fish, in bad cases. Yeast is generally a less common cause of odor, but may produce sour-smelling, yeasty or putrid scents. Trichomonas may also cause a fishy odor.⁸

Changes during Pregnancy

During pregnancy, vaginal secretions may increase considerably, appear bluish-violet in color and take on a thicker consistency. You may also develop varicose veins in the vulvar area which are harmless, but can be quite uncomfortable. If discharge turns watery, it needs to be evaluated because it may represent an incompetent cervix or leakage from the water bag.⁹

Changes with Menopause

In the peri-menopause (three to five year period preceding menopause), you may experience vaginal dryness and/or itchiness, discomfort or pain with intercourse, and both urinary and vaginal infections, along with a host of other symptoms in your body.¹⁰ During menopause, a woman who is not taking hormone replacement therapy may experience thinner and drier vulvar skin. The labia minora may flatten and shrink and the vaginal opening may become smaller. The vagina may become thin and dry, making intercourse uncomfortable or painful.¹¹ Eventually, all of the discharge changes associated with the menstrual cycle cease and discharge is minimal to absent, except in women who take hormone replacement therapy, are of heavier weight or take certain medications, such as tamoxifen.¹²

VULVAR SELF EXAMINATION

While most women know the importance of performing breast self-examinations, few women have heard about vulvar self-examination (VSE). As we previously pointed out, there is a dramatic variance in the appearance of the vulva among women. It is important for you to start performing VSE early, so you can learn what is normal for you and recognize any changes that might occur.

How To Perform VSE

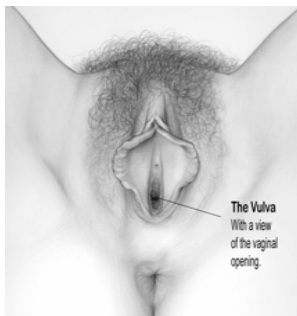
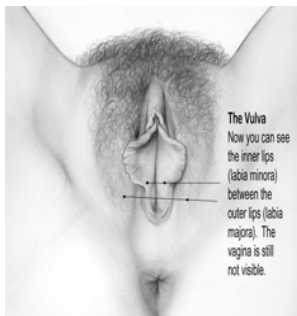
- Perform VSE in a well-lit area.
- Sit down on a comfortable surface, or stand with one foot propped up on a chair or bed.
- Hold a mirror in one hand and use the other hand to examine the vulva.
- Examine the parts of the vulva (through sight and touch): the mons pubis; the left and right folds of the labia majora and minora; the clitoris and its general area; the skin around the vaginal entrance; the perineum; and the perianal area.

What To Look For

- Changes in appearance such as a new mole, wart, lump or other growth; changes in skin color such as white, reddened or brown patches of skin; cuts or sores.
- Changes in the feel of the skin, paying careful attention to areas where you feel pain, itching, or other discomfort.
- During visual inspection of the vulva, apply gentle pressure to the vulvar skin to check for any lumps.

When To Examine

VSE should be performed in between menstrual periods, preferably at the same time each month. All sexually active women and women over 18 should perform VSE. If you notice any changes, you should contact your provider at your earliest opportunity.



UNDERSTANDING VULVODYNIA

Vulvodynia (pronounced VUL-vo-DIN-nee-ah) is chronic vulvar pain without an identifiable cause and affects women of all ages. Preliminary prevalence data from Harvard University suggests that millions of American women experience chronic vulvar pain at some point in their lives. Symptoms include burning, stinging, stabbing, irritation and/or rawness; pain may be constant or intermittent, localized or diffuse. The severity of the condition ranges from mild discomfort to excruciating, disabling pain.

There are other gynecological and skin conditions that cause vulvar pain, and they should be treated or ruled out before a diagnosis of vulvodynia is made. These conditions include (but are not limited to) yeast infections, bacterial infections, and dermatologic conditions such as dermatitis, lichen sclerosus and lichen planus.

The two main subtypes of vulvodynia (which may co-exist) are:

- **Vulvar Vestibulitis Syndrome (VVS)**

Pain is localized in the vestibule and occurs during or after touch or pressure is applied to the area, e.g., during sexual intercourse, tampon insertion, prolonged sitting, etc.

- **Generalized (or dysesthetic) Vulvodynia**

Symptoms may be localized or occur in multiple areas of the vulva, e.g., the labia, vestibule, clitoris, perineum and inner thigh. Pain is relatively constant, but there may be occasional periods of relief. Pressure on the vulva typically exacerbates the symptoms.

What Causes Vulvodynia?

Vulvodynia is not caused by an active infection and is not a sexually transmitted disease. The causes of vulvodynia are unknown due to lack of research on the disorder. Current studies are investigating possible causes and delineating risk factors for developing vulvodynia. Researchers speculate that one or more of the following may cause, or contribute to vulvodynia:

- an injury to, or irritation of, the nerves that supply sensation to the vulva
- an abnormal response of different cells in the vulva to environmental factors such as infection or trauma
- genetic factors associated with susceptibility to chronic vestibular inflammation
- a localized hypersensitivity to Candida (yeast)
- spasms of the muscles that support the pelvis

How is Vulvodynia Diagnosed?

After taking a medical history and asking questions about your symptoms, your provider will carefully examine the vulva, vagina and vaginal secretions to rule out an active infection or skin disorder. Routine cultures for yeast and bacterial infections should be performed. Different areas of the vulva may be touched with a cotton-tipped applicator to determine the location and severity of pain. If any areas of skin appear suspicious, your provider may examine them more closely with a special instrument or take a biopsy of the area.

Is Vulvodynia Associated with Other Disorders?

Some women who have vulvodynia suffer from other disorders such as interstitial cystitis, chronic fatigue syndrome, fibromyalgia or chronic back pain. Because there is minimal research in this area, it is unknown whether or not there is an association between vulvodynia and any other disorder.

What Types of Medical Specialties Provide Care for Patients?

Since vulvodynia is a pain condition that affects the vulva, many experts favor a multi-disciplinary approach to its treatment. Treatment may involve visiting a gynecologist (or vulvovaginal specialist), dermatologist, neurologist, pain management specialist, urogynecologist, and/or physical therapist. Also, because vulvodynia may affect social, sexual and/or emotional aspects of a woman's life, some choose to include a psychologist or sex therapist on their health care team.

How is Vulvodynia Treated?

Treatment is directed towards alleviating symptoms and may provide partial or complete relief. Some patients experience relief with a particular treatment, while others do not respond to that treatment and/or experience unacceptable side effects. **No single treatment is appropriate for every patient** and it may take a considerable amount of time to find a treatment (or combination of treatments) that will alleviate your pain.

Current treatments include:

- **Discontinuation of irritants**
Health care professionals recommend eliminating over-the-counter feminine products such as perfumed bubble baths, soaps, sprays, and douches that may irritate vulvar tissue. This is often the first step in treatment.
- **Local anesthetics, e.g., Xylocaine**
Topical anesthetic cream or ointment may be applied directly to the vulva for temporary relief of pain (typically used prior to intercourse).

- **Topical estrogen cream**
 Topical estrogen applied to the vulva has been found to increase the health of the tissue, especially when vulvar problems are caused by lack of estrogen. It has also been used in the treatment of VVS in patients who do not lack estrogen.
- **Tricyclic antidepressants, e.g., desipramine, amitriptyline**
 Medications that modify neurotransmitter levels (chemical substances that carry impulses from one nerve cell to another), were originally developed for the treatment of depression, but are also used to alleviate some types of chronic pain. In vulvodynia patients, the dosage is typically lower than that used for the treatment of depression. Sometimes an antidepressant will be combined with other medication and/or treatments such as physical therapy and biofeedback. Antidepressants may be formulated into a cream for topical use.
- **Anticonvulsants, e.g., Neurontin, Tegretol, Trileptal**
 Medications developed to treat seizures have also been found helpful in controlling some types of chronic pain. These oral medications may in some instances be formulated into creams for topical use. Anticonvulsants may be combined with other medications and/or treatments.
- **Nerve blocks**
 The pudendal nerve carries impulses back and forth from the vulva to the spinal cord. Anti-inflammatory and anesthetic medications may be used to inhibit the transmission of pain signals from the vulva. Nerve blocks are primarily used in cases of severe pain. A series of injections (spaced apart) may be given intravaginally or in a space near the spinal cord in the lower back. Most women experience short-term relief, but, in some cases, the result is long-term relief.
- **Physical therapy**
 A physical therapist will evaluate joints, muscles and nerves in the lower half of the body to determine if they are contributing to vulvar pain. Treatment may include exercise, education, biofeedback, “hands on” or manual therapies, such as massage, soft-tissue work and joint mobilization, or modalities such as ultrasound, electrical stimulation, or hot packs.
- **Pelvic floor muscle rehabilitation**
 Some women with vulvodynia have associated pelvic floor muscle weakness or spasm that may either contribute to vulvar pain or be a consequence of vulvar pain. Rehabilitation includes insertion of a vaginal sensor and use of a “biofeedback” machine that gives

you visual feedback on the strength of your pelvic floor muscles while performing daily exercises to normalize their function. This therapy is done by specially trained providers and physical therapists.

- **Diet modification**

Some women find that eating certain foods increases their symptoms and that elimination of these foods reduces symptoms. For example, some women eliminate acidic foods, foods high in oxalate, or foods high in sugar (that promote the growth of yeast). If you want to test for food sensitivity, eliminate one food or food group at a time so you'll know which, if any, are affecting you.

- **Complementary medicine**

There are many therapies often used to promote general health that may be used in conjunction with traditional medical approaches in chronic pain patients. Among the complementary therapies are acupuncture, massage, relaxation techniques and cognitive behavior therapy.

- **Interferon injections (used in VVS patients)**

Interferon is a substance produced by the body that helps to fight infection. A series of vestibular injections of manufactured interferon has provided relief for some women with VVS.

- **Surgery (for VVS patients only)**

Vestibulectomy is a surgical procedure in which the vestibule is removed and vaginal tissue is brought down to cover the excised tissue. The procedure is sometimes recommended for women with vulvar vestibulitis after more conservative therapies have failed to provide relief. Many VVS patients experience significant long-term relief following this surgery.

- **Opioids**

Opioid pain-killers (commonly referred to as narcotics) are sometimes used short-term to manage vulvodynia flare-ups. They may also be used early in treatment to help you alleviate the pain while you and your health care provider are seeking a long-term therapeutic solution. In severe cases, when more conservative therapies fail to provide relief, they may be used on a regular basis.

It is important to keep in mind that more research is being conducted on vulvodynia every year. These studies are investigating both the causes of vulvodynia and the effectiveness of therapies used to treat the condition. Additionally, researchers are gaining insight from other chronic pain research and starting to work on the development of novel treatments for vulvodynia.

Self-Help Strategies for Vulvar Pain

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

Clothing and Laundry

- Wear all-white cotton underwear and loose-fitting pants or skirts.
- Avoid wearing pantyhose (wear thigh-high or knee high hose instead).
- Remove wet bathing suits and exercise clothing promptly.
- Use dermatologically approved detergent such as Purex or Clear.
- Double-rinse underwear and any 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 vulvar area.
- Do not use bubble bath, feminine hygiene products, or any perfumed creams or soaps.
- Wash the vulva with cool to lukewarm water only.
- Urinate before the 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% cotton menstrual pads and tampons.

Sexual Intercourse

- Use a lubricant that is water soluble, e.g., Astroglide.
- Do not use contraceptive creams or spermicides.
- Ask your provider for a prescription for a topical anesthetic (e.g., lidocaine).
- Apply wrapped ice or frozen gel pack to the vulva after intercourse.
- Urinate and rinse the vulva with cool water after intercourse.

Physical Activities

- Avoid exercises such as bicycle riding that put direct pressure on the vulva.
- Limit intense exercises that create a lot of friction in the vulvar area.
- Learn stretching and relaxation exercises.
- Don't swim in highly chlorinated pools and avoid the use of hot tubs.

Everyday Living

- Try using a foam rubber donut for long periods of sitting.
- For temporary relief, apply wrapped ice or frozen gel pack for fifteen minutes, use lukewarm or cool sitz baths.
- If you primarily sit at work all day, intersperse periods of standing.
- Learn some relaxation techniques to use during the day. (*The Relaxation and Stress Reduction Workbook* by Davis, Eshelman and Mc Kay or *The Chronic Pain Control Workbook* by Catalano and Hardin are helpful.)

UNDERSTANDING CHRONIC PAIN

Although chronic pain is prevalent in our society, it is often under-treated by providers and has lacked attention compared to many other health issues. Research!America's 2003 poll revealed that almost 60 percent of Americans suffered chronic or recurrent pain in the past year. If you also consider the impact of chronic pain on sufferers' family members and close friends, its impact is even more widespread. It is very helpful for chronic pain sufferers to have basic knowledge of the body's pain mechanisms in order to describe their symptoms accurately to health care providers and to weigh treatment options.

Acute vs. Chronic Pain

There are two types of pain, acute and chronic. *Acute* pain is a signal that the body has been injured, and most of the time, it disappears when the injury heals. You experience acute pain when you burn yourself or stub your toe. *Chronic* pain is different in that it is long-term pain that may either be caused by an ongoing condition, such as arthritis or cancer, or may not have an identifiable cause. Pain is generally considered chronic when it has persisted for more than three months. Chronic pain may last for months or even years.

How do we "feel" pain?

Pain is an extremely complex biological process that begins in the periphery of the body (e.g., limbs, organs) where it is sensed by nerve endings, or pain receptors. These receptors relay messages from one set of nerve fibers to another, to cells in the spinal cord, and finally to the brain. There are many different types of pain receptors that transmit these messages at different speeds, explaining why you feel different kinds of pain, such as dull, aching, sharp, stabbing, etc. The brain also sends messages back to the spinal cord and nerves that may increase or decrease the severity of pain. *Neurotransmitters* (chemical substances that relay these messages) may act as either pain-relievers or pain-producers. Recent research indicates that individuals produce different amounts of these neurotransmitters, which explains why some people experience more pain than others.

Pain Management

Unrelenting, chronic pain can completely change your life, making it difficult for you to sleep, work, socialize and perform daily activities. It often strains your relationships with family and friends, and may cause depression and hopelessness. There are many treatments available to manage chronic pain including the use of oral and topical medications, physical therapy, nerve

blocks, biofeedback, acupuncture and electrical stimulation. It's important to keep in mind that each person responds individually to available therapies and that no therapy or combination of therapies works equally well for everyone.

Talking to Your Health Care Provider about Pain

It is important to talk openly and honestly with your provider about your pain. Asking for pain relief is not a weakness – it is your right! Following are several tools that may help you communicate with your provider that will assist him/her in prescribing effective treatment for you.

Where is your pain?

Pain may be localized or generalized. If your health care provider doesn't have a diagram that you can fill in, it's helpful to draw a simple diagram and mark the areas where you experience pain.

What does your pain feel like?

Remember, your body has different types of pain receptors, resulting in different types of painful sensations. Describing your painful symptoms in detail can help your provider understand your specific situation. Here are some of the most descriptive words:

Sharp	Dull	Burning	Sore
Throbbing	Shooting	Crampy	Stretching
Tender	Raw	Gnawing	Stabbing
Aching	Prickling	Pinching	Tight

How much pain are you feeling?

Pain is a subjective experience. Because there are no objective tests to measure pain, your provider will rely on you to rate the amount of pain you are experiencing. One of the tools designed for this purpose is a *visual analogue scale* (VAS) on which pain is rated on a scale from 0 (no pain) to 10 (excruciating pain). Another way to record pain is to keep a daily, or even hourly, pain diary in which you note activities associated with different pain levels. It is helpful to take this diary to medical visits so both you and your provider can gain a better understanding of what exacerbates or alleviates your pain. In your pain diary, you should keep track of the following:

Date	What you are doing at the time
Time	Type and amount of medication used
Pain rating (0-10)	How medication affects the pain
Location of pain	Other comments/problems

COPING STRATEGIES FOR CHRONIC PAIN

Having chronic pain typically affects many aspects of your life, so learning to manage pain is just as important for your overall well-being as it is for your physical health. Here are some coping strategies that can help you control pain and some of its consequences.

Acknowledge Your Feelings

You may feel sad, angry, or anxious about the pain itself, as well as its overwhelming impact on your life. Even though anger, blame, guilt, and sadness are normal feelings, they can be paralyzing if they dominate your life. Share your feelings and frustrations with empathic family members, friends and health care professionals. Don't keep your feelings bottled up! Some people find that writing in a daily journal is a good way to express these feelings.

Avoid Negativism and Self-pity

There may not be a current cure for your chronic pain, but you can manage it and improve your quality of life. First you have to accept and deal with the presence of pain in your life. There is a mind-body connection which means that your thoughts and feelings can affect your pain. Self-pity and negative thoughts, i.e., "I'm never going to get better," are destructive because they generate anxiety which, in turn, intensifies the pain. Instead, you need to think as positively as you can and surround yourself with people who can help you keep a positive attitude.

Don't Let the Pain Control You

Sometimes you may feel that your pain has taken control of your life. On the contrary, if you adopt a sense of "ownership" over your pain, you can regain control of your life. It's important not to allow physical limitations to become your sole identity. Instead, focus on your strengths and what you're still able to do. If you concentrate on and develop the positive aspects of your life, you will learn that you can live a rewarding life in spite of chronic pain.

Adopt a Healthy Lifestyle

Developing healthy habits is important for everyone, including those with chronic pain conditions. Eat a balanced diet with lots of vegetables and fruits, and drink an adequate amount of water. It may be helpful to seek the counsel of a nutritionist. Sleep, mood and pain are closely linked and you should make sure you're getting enough restorative sleep. If you have a problem falling asleep because of pain, discuss the problem with your provider. Although many people with chronic pain hesitate to exercise, unused muscles cause more pain than toned, flexible ones. Research also shows that aerobic exercise boosts the body's natural painkillers and enhances mood. Under the guidance of your doctor, identify an appropriate exercise program. Everyday stress can also worsen your pain, so learn how

to reduce and manage it; for example, some people find that meditation reduces stress and pain. Discuss various options with your provider.

Set Priorities and Realistic Goals

Examine what is really important in your life and what you'd like to accomplish. Make a list of what must be done, what you would like to do and what doesn't matter. Set small goals that are within your power to achieve or break down larger goals into smaller, more manageable steps. When you reach one of your goals, give yourself credit and enjoy your success.

Be an Active Participant in Your Care

You and your provider are equally important members of your health care team. Educate yourself and work *with* your providers. Let them know what your goals are and work together to develop a plan to achieve them.

Try a Multi-modal Treatment Approach

There are no simple, easy solutions to chronic pain, but that doesn't mean improvement isn't possible. Many options exist and therapies can be combined to reduce your pain. Work with your providers on a plan that includes both medical and complementary approaches. Because everyone responds differently to treatment, it may take several trials to find the best medication and/or treatment for you. Many people find that a combination of prescription and non-prescription medications, manual treatments such as physical therapy, and alternative approaches such as acupuncture, provide the greatest relief. Psychological counseling should also be considered if you need help gaining control over your pain.

Spend Your Energy Wisely

Pain sometimes imposes limitations on one's ability to perform activities. Some find it helpful to alternate rest and activity throughout the day because "overdoing it" may lead to increased pain. On the other hand, complete inactivity leads to muscle tightness and weakness, which may contribute to pain. You need to find the appropriate balance for you.

Develop a Plan for Flare-Ups

Keep a written record of activities that tend to make your pain worse. Speak with your provider in advance about how to manage these flare-ups. This may include ways to pace or change your activity, developing skills to help you relax or distract yourself, using heat/cold for temporary relief, and/or short term changes in your medications.

Help Others

As you're seeking ways to manage the pain, reach out to other women in need. Sharing what you've experienced may be of great benefit to others, and as a bonus, helping them makes you feel better about yourself.

FACILITATING A HEALTHY RELATIONSHIP

As a newly diagnosed vulvodynia patient, you may have already experienced its effect on your relationship or significant other. Even though your partner may be compassionate, he/she may also be struggling to understand what you are experiencing. Openness in your communication and flexibility will help both of you face this challenge to your relationship.

Communication

Clearly, you are the one experiencing physical pain, but your partner is also affected watching you suffer; he/she may be feeling helpless and having difficulty dealing with the change in your sexual relationship. Continue to talk about your feelings and concerns, and encourage your partner to do the same. If your partner does not share feelings initially, try not to become discouraged. Speak with other women or consider seeing a therapist who specializes in the impact of physical illness on relationships.

Sexual Intimacy

Chronic pain, and especially vulvodynia, often leads to an upsetting disruption in your intimate relationship. Although you may not be able to engage in sexual intercourse as frequently as you used to, or possibly not at all, it doesn't mean that your sexual relationship has to end. In fact, avoidance of all sexual activity typically leads to a loss of desire in both partners, further separating you. Until your pain is under control, your goal should be to maintain some level of intimacy.

You should not feel obligated to have painful penetrative intercourse, because it may lead to an association between sexual activity and pain, and also create feelings of resentment. If you decide to engage in penetrative intercourse, be sure to use a lot of lubrication to eliminate friction, are fully aroused prior to penetration, modify your position to reduce pressure on the sensitive areas of the vulva and limit thrusting time. The use of a topical anesthetic, e.g., lidocaine, prior to intercourse may help reduce the discomfort of penetration. Using an icepack following intercourse may control symptoms. If penetration is painful, explore other forms of sexual activity to maintain intimacy with your partner. There are a variety of non-penetrative sexual activities that provide mutual pleasure and facilitate continued intimacy. Klein and Robbins' book, entitled *Let Me Count the Ways: Discovering Great Sex Without Intercourse*, discusses these alternatives.

For Women Who Do Not Have a Partner

If you are not in a relationship, you may have reservations about starting one or doubts about finding a partner who will understand your condition. Feeling that way is completely understandable, but it shouldn't stop you from dating if you have a desire to do so. Mature, compassionate partners who are able to handle a relationship with someone who has vulvodynia do exist. Keep in mind that you can still have a sexual relationship that is pleasurable and satisfying to both partners without having penetrative sexual intercourse.

GETTING THE MOST OUT OF YOUR MEDICAL VISITS

Effectively communicating with your provider and taking responsibility for your own health is crucial, especially when you are dealing with a chronic condition. As an informed and prepared patient, you can maximize the value of your medical appointment. The following suggestions will help you prepare for future appointments:

Finding a provider

You should feel free to ask whether a provider has experience treating the condition and ask for a referral if necessary. Finding a provider who is experienced, empathic, and willing to work with other health care professionals is best. If you don't live near a vulvodynia expert but have a good relationship with your provider, ask if he/she is willing to learn about the condition and its treatments.

Educate yourself

Learn everything you can about vulvodynia. Reading back issues of the *NVA News* is one of the best places to start. Follow recent treatment and research developments and discuss them with your provider.

Be observant and document

Between appointments, make notes about your symptoms (changes in severity, timing, etc.), reactions to medications and any other details. Consider using a pain diary (see *Understanding Chronic Pain* section).

Prepare for your appointment

Be sure to have your medical records transferred to a new provider well in advance. Make a copy of previous notes you have written and give one copy to your provider, keeping the first copy in front of you during the appointment. This will refresh your memory and ensure you'll bring up the most important points during your visit. Bring along a list of any questions you have and take notes during your visit; ask as many questions as needed to understand your provider's diagnosis and recommendations. Consider asking a close family member or friend to accompany you to the appointment if you think you need their help to remember and interpret what was said. If that isn't possible, ask your provider if you can use a cassette recorder, explaining that this will help you remember what he/she recommends.

Inquire about tests and lab results

If your provider orders lab work, you're entitled to ask why it needs to be performed. Make sure he/she follows up and explains your lab results to you.

Request that your providers communicate with each other

Because chronic pain patients are often under the care of providers from multiple specialties, it is important that the team communicate regularly. Request that a summary of each visit be sent to the other team members.

EMPLOYMENT ISSUES

Depending on the severity of your condition, you may have to deal with some difficult issues in the workplace. Perhaps your current ability to work is compromised or you find yourself having to make excuses for missing work. Many vulvodynia patients are faced with the dilemma of whether or not to discuss their condition with their employer. There is no simple answer to this situation because everyone's work requirements are different. However, here are a few suggestions to guide you through the process.

RESEARCH COMPANY POLICIES AND WORK OPTIONS

Research your company's human resources policies regarding disability, discrimination and employment options. Here are some possible options:

Part-time employment

Part-time employment may reduce stress and allow time for medical visits and trying new treatments without worrying how side effects will affect your work. On the downside, your salary will be reduced and it could affect your eligibility for continued benefits.

Job-sharing

Consider opportunities within your company to create a unique position. Depending on your employer, you may be able to share your position with another part-time employee.

Family and Medical Leave Act (FMLA)

Companies with more than 50 employees must provide up to 12 weeks of unpaid leave throughout one year for a serious health condition or other valid reason. Please see <http://www.dol.gov/esa/whd/fmla/> for more information on your eligibility. Before selecting this option, make sure you understand your company's policies regarding reinstatement to your position, years-of-service accrual and maintenance of benefits while you're away.

Consulting or Temporary Employment

Consulting provides flexibility and an income, thereby allowing you to work when you are well, but may be more stressful because you're responsible for generating your own income, as well as paying for your own health insurance.

Resignation/Layoff

If your employer is inflexible or uncompromising, you can offer to resign. This may or may not result in the negotiation of a reasonable alternative. Before resigning, find out if there is a layoff plan (force management program). If this option is available, you can volunteer to leave before retirement, with the benefit of receiving some type of pension, possibly a severance package, and limited continuation of health insurance.

Disability

Going on disability is the most extreme option, but may be necessary if your pain is severe and incapacitating. For information on applying for disability,

please visit: <http://www.ssa.gov/disability/>. The Disability Workbook for Social Security Applicants by attorney Douglas Smith is also helpful.

DISCUSSING YOUR CONDITION WITH YOUR EMPLOYER

Whether or not you perceive your employer as understanding and empathic is likely to influence your decision to reveal your condition. The length of time you have been working in a particular place is also likely to be a factor. Each work situation is unique, but it may be helpful to consider the following in weighing the decision to tell your employer:

Why do you want to discuss it?

First you should consider your reasons for telling your employer. Do you want to reduce your hours or take sick leave? Do you want to be transferred to a less stressful position? Do you want to explain why your performance has been impaired or why you have been calling in sick?

How much should you share and with whom?

Consider what you would need to know if someone working for you had a health problem. If you are asking for a change in your employment status, your supervisor will have to tell his/her supervisor. You are not usually required to divulge a medical condition unless you are taking extended leave; however, in this case, you may have to provide human resources with a confidential diagnosis from your provider. If you work closely with others, you may want them to know that you have a physical condition that sometimes interferes with your attendance or performance. You do not have to go into details; you can say, "I want you to know I have a chronic pain condition so you'll understand why I may not be here at certain times."

How do you talk about vulvodynia with your employer?

Schedule a 30-minute meeting with your employer to discuss a personal issue. You may want to do this on a Friday, so that he or she has time to think about it over the weekend. At the beginning of the meeting, request strict confidentiality. If your boss has to report to his or her supervisor or human resources, discuss how you would like it presented to others. You may want to begin the discussion with a statement indicating that you are committed to your job and are willing to work hard. Explain that you have a chronic condition that is more manageable on some days than others and assure your employer that you are doing everything you can to seek proper treatment. If you are uncomfortable discussing it, you don't have to be specific about your diagnosis. You can simply say that you suffer from chronic pain, and if you are prodded for more information, a phrase like, "I'm just learning about it myself," may terminate the inquiry.

Most women with vulvodynia have good and bad days. If you are currently employed, you do not necessarily have to resign to pursue treatment. Try to work at a level that allows you to manage your pain and care for yourself, while maintaining financial security and an adequate level of health insurance.

ADVICE FROM VULVODYNIA PATIENTS

An ongoing University of Alberta study is examining ways in which long-term vulvodynia affects women's lives. Following are some vulvodynia patients' responses to the question, "If you could give advice to a young woman who is told that she has vulvodynia, what would you tell her?"

"Be strong, be patient, have hope."

The most common theme was the importance of personal strength in living with vulvodynia. Personal strength was defined as both the persistence to keep searching for ways to alleviate the pain and the courage to assert oneself and insist that others take your pain seriously. The most common piece of advice, mentioned by nearly every respondent, was that women with vulvodynia should "never give up." Many respondents identified "personal strength" as a characteristic they acquired from having vulvodynia.

"Don't hesitate to share what you have learned and discuss whether a new treatment might be right for you."

The second most common theme was the importance of developing a supportive, but not unquestioning, relationship with a health care provider. Finding the right personal fit with a provider was considered crucial. The importance of finding a provider who respects his or her patients' priorities and knowledge about her own condition was also stressed. Many respondents suggested that you find a balance between your own knowledge of your symptoms and your providers' medical expertise.

"Become as informed as you can."

The third most common theme was the importance of learning as much as possible about vulvodynia. Respondents said that they would advise other women to check out online medical databases and medical libraries, and to assume the responsibility for learning about emerging treatments (but to remember there is no "one size fits all" treatment). Being informed about vulvodynia was considered essential for building a relationship in which you and your provider can work as a team.

"Communicate openly and frequently with other women in this situation so that you do not feel isolated."

The fourth most common theme was seeking out other women with vulvodynia. Many women identified isolation as one of the largest threats to their emotional well-being and felt that connecting with other women was a way to combat the isolation, as well as share medical information.

For more information about this study, including how to participate, please visit: www.humanities.ualberta.ca/survey/vulvodynia.htm

REFERENCES

The NVA extends its appreciation to the following people and institutions for allowing the NVA to adapt printed materials for this guide.

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For further information on many topics discussed in this guide, please visit the NVA's web site, www.nva.org, to view summaries of back issues of *NVA News*, the NVA's educational newsletter. (Click on *Newsletters* on the left side of the home page.)

SUPPORT THE CAUSE AND GET INVOLVED

As women with vulvodynia, we are in a unique group that relies on each other for ongoing support and encouragement. It is also essential that we work collectively, combining our skills, talents and assets to ensure that attention be paid to this condition. The NVA was started by five patients ten years ago and is one of the only nonprofit organizations in the world dedicated to improving the lives of women who suffer from vulvodynia.

How Does the NVA Help You?

The NVA **educates** patients, providers and the general public. The more you learn about chronic vulvar pain, the better-equipped you will be to speak with your provider about your options. The NVA publishes both printed and electronic newsletters that will keep you up-to-date on the newest vulvodynia research findings and treatments. We also help by developing informational materials and programs specifically for the providers that women routinely visit. Because many women find that speaking to others who have vulvodynia is a good source of information and a way to overcome the emotional isolation, the NVA has established a **support network** across the U.S. (and a few other countries) and can refer you to a support contact in your local area.

The NVA maintains a **database of health care providers** who are experienced or interested in the treatment of chronic vulvar pain disorders. A list of your local providers is available upon request to NVA donors. The NVA also directly funds pilot research studies and works with members of Congress and the National Institutes of Health (NIH) to encourage increased **federal funding of vulvodynia research**.

How Can You Make A Difference?

You may feel that you are just one person and that there isn't much you can do to make a difference. Not true! Recent research indicates that *millions* of women in the United States alone suffer from vulvodynia. By combining our voices and skills into one collective body, we can make a significant impact, changing the future for ourselves and those who will come after us. Please make a donation, volunteer your time or continue to be a source of encouragement to others after you are feeling better.

For more information:

National Vulvodynia Association
PO Box 4491
Silver Spring, MD 20914
301-299-0775
301-299-3999 (fax)
www.nva.org

