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

A Self-Help Guide for Partners of Women with Vulvodynia

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Acknowledgement:
Special thanks to Holly Sullivan for her assistance in researching and writing this guide.

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.

Introduction

As the partner of a woman with vulvodynia, it is important to know that the two of you can still have a close and fulfilling relationship. Of the millions of couples who have faced this challenge, many have found that it can strengthen a relationship when the affected woman's partner is supportive and compassionate.

Although there has been research and treatment progress in the vulvodynia field, some health care providers are still unfamiliar with its diagnosis. The first vulvodynia prevalence study (2003) found that 60 percent of vulvodynia sufferers consult at least three doctors in seeking a diagnosis and that 40 percent remain undiagnosed after three medical consultations. Clearly, this is a very frustrating process for women and their partners. Since genital conditions are not openly discussed, many women with vulvodynia feel isolated. Of the thousands of vulvodynia sufferers surveyed, only 25 percent reported feeling comfortable discussing the condition with their closest female friends. Thus, simply listening to your partner when she expresses her feelings and concerns can make a big difference.

The National Vulvodynia Association created this guide to encourage you to learn more about vulvodynia and to help you deal with relationship issues that many couples face. It is important to note, however, that the impact of vulvodynia varies among affected women. For example, a woman who experiences pain solely with sexual activity is still able to work and run errands, but a woman who suffers from constant, severe pain is limited in what she can do. Since this guide covers all types of vulvodynia, you may choose to skip sections that do not apply to you and your partner.

Section I: Understanding Vulvodynia

Vulvar Anatomy

The vulva is the external part of the female genital tract that protects a woman's sexual organs, urinary opening, vestibule and vagina, while also functioning as the center of a woman's sexual response. The vulva is different from the vagina, which is the passageway that begins at the vaginal opening (introitus) and ends at the cervix, or lowermost part of the uterus. Each woman's body is unique, and just as there are different body shapes, the appearance of the vulva differs from woman to woman.

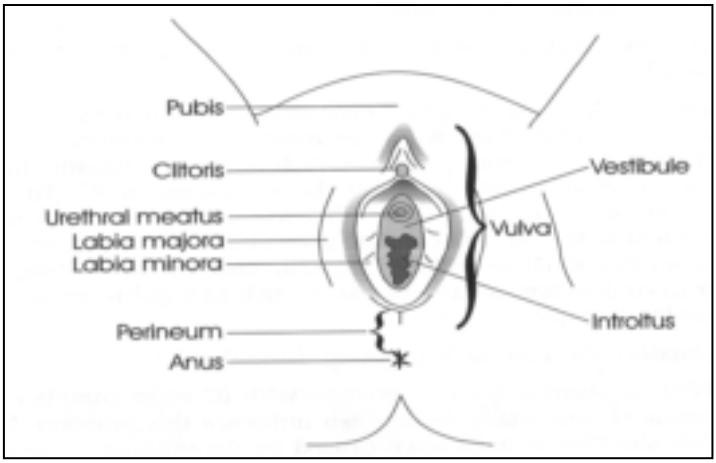


Diagram reproduced with permission from The Interstitial Cystitis Survival Guide by Robert Moldwin, MD, New Harbinger Publications, Inc. © 2000.

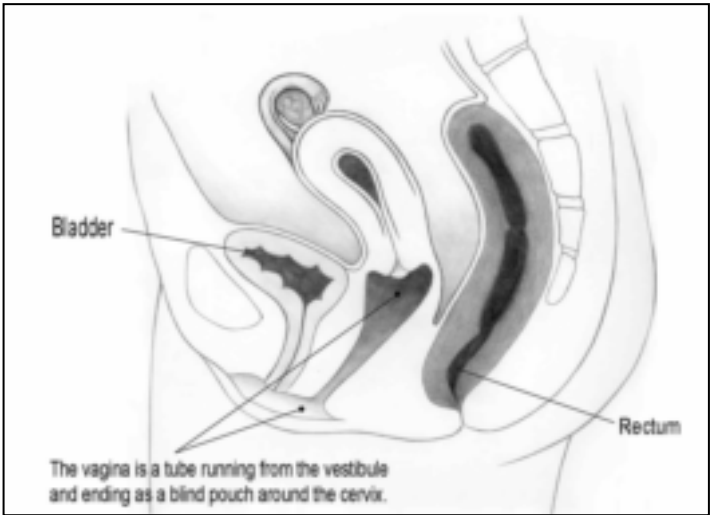
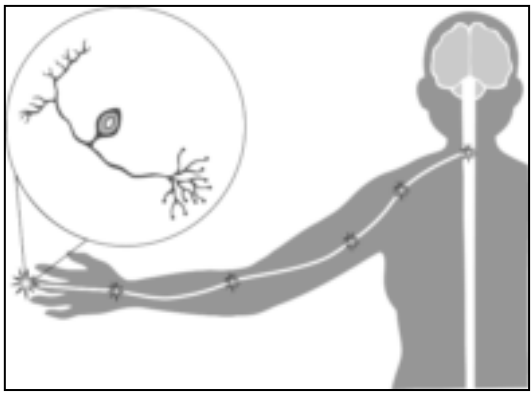


Diagram reproduced with permission from The V Book by Elizabeth Stewart, MD and Paula Spencer (Illustrations by Dawn Danby and Paul Waggoner), Bantam Books, 2002.

How We Feel Pain

Pain is a complex physiological process. As seen in the diagram, when pain receptors are triggered, specialized nerves carry a pain “message” to the spinal cord and the brain.



Once the brain has received and interpreted 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 can signal the release of internally produced painkillers known as endorphins. Alternately, the brain can direct the release of chemical messengers or hormones that 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, causing 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 quickly once the injury heals. Sometimes, however, your body heals, but your brain continues to perceive pain. For an unknown reason, acute pain can become chronic.

The majority of medical providers define *chronic pain* as pain that has persisted for at least three to six months. 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.

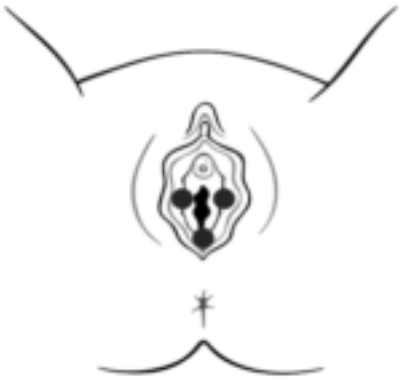
What Is Vulvodynia?

Vulvodynia is chronic vulvar pain *without a clear identifiable cause*. It is not caused by an active infection, skin disorder or sexually transmitted disease. Vulvodynia's severity, degree of constancy and location vary among affected women.

The two main subtypes of vulvodynia, which sometimes co-exist, are:

Provoked Vestibulodynia (PVD)
(aka Vulvar Vestibulitis Syndrome)

PVD is characterized by pain limited to the vestibule, the area surrounding the vaginal opening. It occurs during or after pressure is applied to the vestibule, e.g., with sexual intercourse, tampon insertion, a gynecologic examination, etc. It is further classified as *Primary* or *Secondary*. Women with *Primary PVD* experience vestibular pain from their first attempt at vaginal penetra-tion. Women with *Secondary PVD* have experienced pain-free sexual intercourse prior to developing pain.



Generalized Vulvodynia

For women with Generalized Vulvodynia, pain occurs spontaneously and is relatively constant, but there may be some periods of symptom relief. Activities that apply pressure to the vulva, such as prolonged sitting or simply wearing pants, typically exacerbate symptoms. Some women experience pain in a specific area, e.g., only in the left labia or near the clitoris, while others experience pain in multiple areas, e.g., in the labia, vestibule, and clitoris, as shown in the diagram.

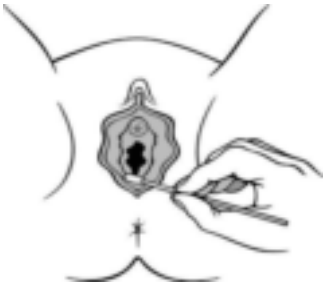
What Causes Vulvodynia?

Vulvodynia is not caused by a vulvovaginal or sexually transmitted disease, so it's not contagious. Through continued research efforts we are moving closer to uncovering its underlying cause(s). 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
- An increase in the number of "pain-sensing" nerve fibers in the vulva
- Elevated levels of inflammatory substances in the vulva
- An abnormal response of certain cells to environmental factors such as infection or trauma, e.g., pelvic injury
- Genetic susceptibility to chronic vulvar inflammation, widespread body pain and/or an inability to combat infection
- Pelvic floor muscle weakness, spasm or instability

Diagnosis

A gynecologist, urogynecologist or other provider knowledgeable about vulvodynia should perform your partner's first examination to rule out other conditions with similar symptoms, e.g., yeast infection. Then, based on her symptoms, she may be referred to another specialist for continued care.



After taking a thorough medical history and asking specific questions about your partner's symptoms, the gynecologist should carefully examine the vulva, vagina and vaginal secretions to rule out an active infection or skin disorder. He/she will likely perform a cotton-swab or "q-tip" test (pictured on the left), during which gentle pressure is applied to various vulvar sites and the patient is asked to rate the severity of the pain. If any areas of skin appear suspicious, the provider will examine them with a magnifying instrument or take a biopsy of the area. He/she may also recommend that blood be drawn to measure estrogen, progesterone and testosterone levels.

Prior to your partner's appointment, she should consider downloading and completing the pelvic pain questionnaire created by the International Pelvic Pain Society (http://www.nva.org/shg1). In addition, she can complete and bring her pain diary to her appointment. (To download a sample diary, visit: http://www.nva.org/paindiary.)

Co-Existing Conditions

Some women with vulvodynia may suffer from other disorders, such as interstitial cystitis (painful bladder syndrome), irritable bowel syndrome, fibromyalgia, temporomandibular joint and muscle disorders, endometriosis and/or chronic fatigue syndrome. If your partner suffers from another chronic pain condition, she should describe her symptoms to her provider, even though she may not think they are related to the vulvar pain. Detailed information on these conditions can be viewed at www.chronicpainresearch.org.

Treatment

Since vulvodynia is a pain condition affecting the genital area, and often involves the pelvic muscles, experts favor a multi-disciplinary approach to its treatment. Your partner may visit a gynecologist, dermatologist, neurologist, pain management specialist, urogynecologist, and/or physical therapist. This condition often affects a woman's sexual relationship and emotional well-being, so a provider may recommend consulting a couples therapist or psychologist.

Initial treatment is directed at alleviating the pain and may be partially or completely successful. No single treatment is appropriate for all affected women. In most cases, learning the most effective ways to manage the pain is a gradual process, and typically involves a combination of treatments. Some women experience relief with a particular treatment, while others do not respond to it and/or experience unacceptable side effects. Current treatment methods include oral "pain-blocking" medications, topical medications applied to the vulva, pelvic floor muscle therapy, nerve blocks, neurostimulation, and injection of topical steroids, anesthetics or other medications. In some cases of Provoked Vestibulodynia, surgery is recommended.

Although progress may not be noticeable on a day-to-day basis, most women will eventually find a treatment regimen that relieves their pain. The more you learn about vulvodynia, the more supportive you can be while your partner works with health care providers to find effective treatment.

Section II: How You Can Help

Even if you feel frustrated by your inability to lessen your partner's pain, you can still make a big difference by being supportive and reassuring your partner that you will face the situation together. Your participation is critical to your partner's emotional well-being and to the health of your relationship.

Although it is slowly starting to change, conditions affecting a woman's genital area are not openly discussed. As a result, many women with vulvodynia feel ashamed and embarrassed that they have this condition. Although it may be difficult to imagine what your partner is experiencing, you can still be a willing listener and encourage her to seek effective treatment. Sometimes simple tasks feel overwhelming when a person suffers from ongoing pain, so you might offer to take over some daily chores. Ask your partner if there are any stressful situations that she would like you to handle, such as dealing with your health insurance company. This topic is covered in greater detail in the next section.

As already mentioned, educating yourself about vulvodynia and its treatment is essential. The fact that you are reading this guide shows that you are interested in your partner's physical and emotional well-being. Learning about vulvodynia equips you to discuss treatment options with your partner and her health care provider.

You can advocate for your partner by accompanying her to medical appointments. If you offer to accompany her and she declines, that's okay. Your offer will mean a lot to her. If you do accompany her, it's up to the two of you to decide what role you will play. For example, you may choose not to be present during the physical examination, but participate afterwards when the clinician discusses the findings. Since health care providers are sometimes rushed, you can help your partner develop a list of questions before the appointment and make sure they are answered during the visit. Some women are upset after the medical exam because it exacerbates the pain and may have a difficult time concentrating on the provider's instructions. It helps if you listen to the recommendations and take notes. By participating at medical visits, you can help your partner recall information and better equip both of you to discuss treatment options.

Finally, because vulvodynia often impacts sexual relationships, many sufferers need reassurance from their partner that they are still loved. It is a critical time to show your affection by leaving a sweet note, sending a mid-day email, giving her flowers, etc.

Section III: Coping with Lifestyle Changes

Having a partner who suffers from vulvodynia may require some lifestyle adjustments that are difficult for a couple to accept. Depending on the severity and constancy of your partner's pain, she may have difficulty sitting for extended periods, participating in social functions and/or carrying out daily chores. In some cases, her ability to work and take care of children may be compromised.

Both of you may have to adjust expectations of how much she can do, especially during pain flare-ups. Remember, even if your partner's pain is unrelenting today, with medical care and perseverance, it is likely to improve.

Vulvodynia can impact the following areas of a couple's relationship:

— **Household Responsibilities**
Couples develop a pattern for handling household responsibilities, so when one partner develops chronic pain, this pattern is usually disrupted. Seeking medical treatment for vulvodynia, plus the side effects of medication, may lessen the time and energy your partner has to devote to household responsibilities. It is likely that you will have to carry the extra load until your partner finds a way to manage her condition. The two of you should discuss which tasks or responsibilities she needs you to handle. For women whose pain is exacerbated by sitting, chores that can be done while standing may be the most comfortable. Also, ask your partner if there's a certain time of day when her pain worsens, so you can take over chores during that period. If you can afford it, discuss hiring outside help, or sometimes you may want to ask a family member or friend to pitch in.

— **Parenting**
Parenting roles may be affected when one partner suffers from a chronic pain condition. Whether your partner works at home or in an office (or not at all), dealing with the challenges of raising children are understandably more difficult when someone is in pain. If possible, ask a family member or close friend to assist with child care duties during difficult periods. Perhaps you can hire 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 have some feelings and concerns about their mom's condition and their schedule changes. Even young children notice when a parent isn't feeling well, lacks patience or cannot sit for long periods of time. Whether the two of you decide to disclose your partner's condition to your children or not, they will know that something is wrong. If you don't tell them, you run the risk that they will arrive at their own conclusions, e.g., they may think that their

mom has a life-threatening illness. Of course, the amount of information a child needs depends on his/her age and ability to understand. You should speak simply and honestly and let your children know how they will be affected.

Here are some practical suggestions for speaking with your children:

- Give a very simple description of your partner's condition.
- Emphasize that the pain is not the child's fault and is not contagious.
- Assure them it's not life-threatening and that the two of you are working with the doctor to help her feel better.
- Let your children know that pain can be unpredictable, i.e., that sometimes mom may be fine, but other times she may not be able to participate in certain activities.
- Talk about any scheduling changes you have to make while your partner seeks care. Tell them who will take care of their needs, such as picking them up from school.

— **Career Changes**

Fortunately, most women with vulvodynia are able to continue working, even though some adjustments may have to be made, e.g., she may need to do more tasks standing. Your partner should decide whether it is necessary to have a confidential talk with her employer. Her goal is to devise a work strategy that allows her to manage her pain and maintain financial security and adequate health insurance. If additional home and childcare responsibilities are affecting your work, you may decide to speak with your employer also.

If your partner's pain is severe, she may not be able to concentrate, sit for long periods of time, travel and/or socialize at work functions. Thus, she may have to take a temporary leave of absence or resign from her position. (Women who need to apply for disability benefits can view the NVA's guide, *How to Apply for Disability Benefits,* at www.nva.org/disability.)

It will likely take some time for your family to adjust to certain lifestyle changes. If you or another family member is feeling anxious or depressed, you should consider consulting a family therapist, particularly one who specializes in the impact of chronic illness on families.

Section IV: Maintaining Sexual Intimacy

Not all women with vulvodynia experience the same difficulties with sexual activity. Women whose pain is localized to the vaginal opening usually find penetration very painful, but may enjoy external genital stimulation. Alternately, women whose vulvar pain is not near the vaginal opening may be comfortable with penetration, but have pain with external stimulation of other areas.

As a couple, you and your partner must accept that vulvodynia, to some extent, is going to affect your sexual relationship. In the beginning, it is impossible to know how long the situation will last. Both of you may need help dealing with the emotional and psychological consequences that result from the change in your sexual relationship. It is critical that you and your partner endeavor to maintain physical and emotional intimacy when you cannot engage in sexual intercourse. Other types of intimacy include hand-holding, cuddling, kissing and meaningful conversations.

Many couples affected by vulvodynia experience similar feelings when their sex life is disrupted, including:

— **Emotional Reaction to Change**
A change in your intimate life is difficult for both partners. Both of you may feel frustrated, angry, sad, disappointed or helpless. It is important to recognize and discuss your feelings with your partner, before they create emotional barriers and prevent future intimacy.

— **Fear of Initiating Sex**
When sexual activity causes pain for an extended period of time, the body learns to "expect" pain with sexual activity. Often, the association between pain and sex remains well after the pain is under control. Your partner may be afraid that sex will be painful or that it will cause a pain flare-up. As a result, she may not be affectionate, fearing that you will interpret a hug or kiss as a sign that she wants to be sexually intimate. Partners also experience anxiety, worrying that their actions will cause or exacerbate their loved one's pain; as a result, they may stop initiating sexual relations. Fear of rejection is another reason that partners stop initiating sex. No one likes to be rejected, even for an understandable reason. If you never initiate sexual relations, however, it may make your partner feel undesirable. It's important to recognize and discuss this potential cycle of rejection.

— **Desire Issues**
All types of chronic pain affect a person's desire to engage in sexual relations. Depression, a common consequence of living with chronic pain, may also interfere with desire. In addition, medications used to treat pain and depression, e.g., antidepressants, can lessen desire. If your partner doesn't show any interest in sex, it's important for her to discuss it with you and her doctor.

Start Talking About It

Communication is the key to a healthy relationship and sex life for all couples. Many people are uncomfortable discussing sex, however, or assume that their partners already know their preferences. How can you know which types of sexual stimulation your partner enjoys without asking? Conversations about intimacy become especially important when your sex life is challenged by a chronic pain condition. Discussing your concerns and fears, and what is painful or pleasurable, can lay the groundwork for a satisfying sexual relationship. At first, this type of conversation may make you uncomfortable, but it will get easier with practice.

Here are some suggestions for facilitating productive communication:

— **Timing and Location**
It's important to establish a time and location for this conversation. In general, you should avoid springing sensitive issues on your partner. Let her know in advance that you would like to set aside time to talk about your intimate relationship. You should not have this conversation during sexual intimacy, on a romantic date, or prior to a social engagement.

— **Write Down Your Feelings**
Writing down what you want to say beforehand is a good way to clarify your feelings. It can also help you to practice the best way to express what you are feeling.

— **Create Safety and Show Respect**
In order to disclose very private feelings, both of you need to feel safe. Since the conversation is likely to involve a discussion of novel sexual activities to try, you should agree beforehand not to embarrass or laugh at each other's suggestions.

— **Listen Without Interrupting**
Learning not to interrupt isn't easy, but it is very important to intimate communication. Agree not to interrupt. If you make a mistake, apologize and focus on listening until your partner is finished speaking. One way to eliminate interruptions is to use a random object, which is held by the partner who is speaking. When finished, he/she hands the object to the other partner. Be sure to jot down points you want to respond to while your partner is speaking.

— **Make "I" Statements**
Try to avoid making statements about how your partner 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 are blaming your partner.

— **Be Specific and Ask Questions**
Try to avoid sweeping statements such as, "You always reject me," or, "I'll never be able to do that." Be as specific as you can in your descriptions. If your partner makes general statements, ask her to be more specific to help you understand. You should also ask questions.

— **Time-Outs**
Before you start a discussion, agree that either of you can ask for an intermission or to end the conversation. You should also agree to resume the conversation at a later time.

— **Agree on Confidentiality**
Since discussing your sexuality is such a private matter, you have to agree on the confidentiality limits of your conversation. For example, is it okay for your partner to share your conversation with her sister or best friend? It is crucial to respect the agreed-upon restrictions.

— **Schedule Another Time to Talk**
Conversations about sexual intimacy need to be an ongoing process, because it is unlikely that you will completely resolve an issue in one sitting. Before you end your conversation, schedule a future time to revisit the issue.

Now that we have covered communication ground-rules, here are some issues you may choose to discuss:

— **Satisfaction with Intimate Relationship**
How satisfied were both of you with your sexual relationship prior to your partner's vulvodynia? Were there conflicts that predated her condition or did both of you have a high level of satisfaction with your intimate relationship? How has vulvodynia changed your sex life? For example, has your partner become fearful that sexual activity will increase her pain? Is the pain causing her to avoid intimacy? Do you fear that you'll hurt her during sexual activity? Do you feel rejected because she doesn't initiate sex?

— **Painful or Pleasurable**
It's important for your partner to show you which vulvar areas elicit pain when touched. She can do that herself or ask her doctor to identify the areas during a medical appointment. Which parts of her body and vulvovaginal area give her pleasure when touched? In

addition to location, which sexual activities give her pain or pleasure? Which sexual positions does she find most comfortable and enjoyable?

— **What Do <u>You</u> Enjoy?**
If you haven't already done so, tell your partner what you find pleasurable. A simple aid to start this conversation is a foreplay map (http://www.nva.org/shg5). In this exercise, you label body parts in the order you would like 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 the results.

— **Redefining 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 does not necessarily equal intercourse. Your partner should never feel obligated to engage in painful penetrative intercourse, especially since it can lead to an association between sex and pain. There are a variety of non-penetrative sexual activities that can provide mutual pleasure and help to maintain intimacy. (See the Resources section for books that discuss alternatives.) Keep an open mind and you may find that trying new sexual practices adds some excitement to your relationship.

— **Plan Ahead for Pain Flares**
It is common for flare-ups to occur, during which sexual intercourse, and perhaps other sexual activities, are out of the question. It is helpful for you and your partner to discuss how to handle this situation ahead of time to lessen feelings of rejection. During these periods, you can agree to a different kind of sexual closeness or non-sexual ways of expressing intimacy.

— **Gestures of Affection**
Therapists recommend that both of you compose a list of non-sexual gestures that make you feel loved and valued. For example, your partner's list might include accompanying her to medical visits, holding her hand, or giving her flowers. 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 maintaining closeness in your relationship.

More Suggestions for Keeping Sexual Intimacy Alive

— **Schedule a Time**

Many couples believe that sexual intimacy should occur on the spur of the moment, without planning. As a relationship progresses, even without vulvodynia, spontaneity dissipates due to work responsibilities, children and other commitments. Most couples find that they need to schedule a time for closeness. Plan ahead and make a 'date' with your partner that works for both of you. Schedule some relaxing time together that enables you to slowly begin your rediscovery process.

— **Exploration and Foreplay**

Create a relaxing environment by lighting candles or playing soft music. If it has been a long time since you've been intimate, set some limits. For example, you can agree to engage in a touching session that avoids the vulvovaginal area. Your goal is to feel comfortable and simply enjoy sensual pleasure by exploring each other's bodies. This session may include petting, caressing, stroking, kissing and massaging. Foreplay does not have to be just a prelude to sexual intercourse. 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 try using a finger first to gauge your partner's reaction. Choose a time of day when she experiences the least amount of pain. Use a lot of lubrication to eliminate friction and make sure she is fully aroused prior to penetration. Choose a position that reduces pressure on the sensitive vulvar areas and limit thrusting time. If helpful, she can support herself with a pillow. The use of a topical anesthetic prior to intercourse, e.g., lidocaine, helps to relieve the pain of penetration. She should let you know what causes pain and show you other ways to touch her that are not painful.

— **Reintroduce Spontaneity**

Once your partner's pain is under control for a period of time, she can let you know that she is doing well and would be receptive to future sexual activity. Knowing that she is interested in sexual intimacy may help to revive some of the spontaneity in your sexual relationship. As always, it is important to let her know that you find her desirable.

Section V: When to Seek Counseling

Some couples find the change in their relationship so unsettling that they decide to consult a therapist. Even couples that are coping quite well can benefit from speaking with an experienced therapist. It is also possible that you would like to speak with a therapist yourself to discuss how your partner's condition is affecting you. If you would like to visit a couples or sex therapist with your partner, discuss it with her. Remember that you are not the first couple to face this challenge – it's okay to ask for help.

To find a knowledgeable therapist or counselor in your area, your partner should ask her health care provider for a referral. You can also visit the web sites of professional organizations, such as the American Association of Marriage and Family Therapists (www.aamft.org) or the American Association of Sexuality Educators, Counselors and Therapists (www.aasect.org). Before making an appointment, contact different therapists and ask about their experience dealing with couples facing chronic illness and/or sexual intimacy issues related to chronic pain.

Conclusion

We hope that this guide has been helpful and reassures you that you and your partner are not alone. Vulvodynia presents varying degrees of physical, emotional and sexual challenges, but it is still possible for you and your partner to have a rewarding relationship and family life. We encourage you to visit our web site, www.nva.org, to learn more about the NVA's resources and activities.

Resources

Books (see www.nva.org/bookstore)

— Bilheimer, Susan and Echenberg Robert. *Secret Suffering: How Women's Sexual and Pelvic Pain Affects Their Relationships*, Susan Bilheimer, 2019.

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

— Herrera, Isa. *Ending Female Pain: A Woman's Manual*, Duplex Publishing, 2014.

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

Articles (see http://www.nva.org/newsletters/)

— McGrath, NL. Understanding Sex Therapy for Vulvodynia. NVA News, Vol. XVII, Issue II (2012).

— Connor, J. "The Impact of Provoked Vestibulodynia on Couples." NVA News, Vol. XIV, Issue I (2008).

— Foster, D. and Kotok, MB. "Vulvodynia's Psychological Impact on the Partner." NVA News, Vol. XII, Issue II (2007).

— Buehler, S. and Seeberger, C. "Sex Therapy in the Treatment of Vulvodynia" NVA News, Vol. XII, Issue I (2006).

— Kellogg-Spadt, S. and Sernekos, L. "A Discussion of Sexual Intimacy and Vestibulitis." NVA News, Vol. VIII, Issue III (2003).

— Kellogg-Spadt, S. and Sernekos, L. "Dysesthetic Vulvodynia and Sexual Intimacy." NVA News, Vol. IX, Issue I (2003).

— Wittke, L. "Sexual Intimacy and Vulvodynia." NVA News, Vol. VIII, Issue I (2002).

Web Site

— NVA's online vulvodynia tutorial, ***Everything You Need to Know About Vulvodynia***, http://www.nva.org/learnpatient/

Self-Help, Pregnancy and Disability Booklets

The NVA has created three additional educational booklets that individuals can view at www.nva.org/shg.

Vulvodynia: A Self-Help Guide

This self-help guide enables women with vulvodynia to make educated decisions about their health care, build strong partnerships with their health care providers and improve their quality of life. It provides a comprehensive overview of the condition from both the gynecological and chronic pain perspectives. In addition to focusing on the diagnosis and treatment of vulvodynia, it features important self-help tips and coping strategies.

Vulvodynia, Pregnancy and Childbirth

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 pain during pregnancy and minimizing trauma to the vulva during childbirth. The booklet also discusses alternative methods of conception and childbirth options.

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.

About the NVA

Founded in 1994 by a small group of patients, the NVA is a nonprofit organization dedicated to improving the lives of women with vulvodynia.

The NVA has established a number of programs and services including:

Educational Resources

The NVA maintains online learning programs for patients and health care providers (http://www.nva.org/learnpatient/), and disseminates newsletters (http://www.nva.org/newsletters/) that will keep you up-to-date on the latest vulvodynia research findings and treatments. Our newsletter also contains valuable articles on emotional and sexual issues related to vulvodynia.

Support Services

Women find that speaking to others who have vulvodynia is both a good source of information and the best way to overcome the emotional isolation that often accompanies this disorder. To facilitate this, the NVA oversees a support network across the US and some foreign countries.

Health Care Provider Referrals

The NVA maintains a database of health care providers who are knowledgeable about the diagnosis and treatment of chronic vulvar pain disorders.

Research Funding

The NVA directly funds pilot research studies and collaborates with Members of Congress and the National Institutes of Health (NIH) to promote increased federal funding of vulvodynia research.

To learn more about all of our programs and activities, please visit http://www.nva.org.

For more information:

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