



National



Vulvodynia



Association

NVA News

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Navigating Intimate Relationships

*This article was adapted from a chapter in the 2nd edition of *When Sex Hurts* by Andrew Goldstein, M.D., Caroline Pukall, Ph.D., Irwin Goldstein, M.D., and Jill Krapf, M.D.*

Once the chronic pain began, just wearing underwear, sitting through a movie, or driving a car was enough to trigger excruciating irritation. Of course, intercourse was completely out of the question for me. For two years, my husband didn't touch me. He didn't kiss me, hug me, or hold my hand. He refused to go for counseling or try other forms of intimacy. Although there were other problems in our relationship, I know that my divorce was due in large part to our inability to have sex.

— SHELLEY, THIRTY-NINE

How do you tell someone you're dating that you can't have sex?

— AMY, TWENTY-EIGHT

As if relationships aren't complicated enough, when you add vulvodynia and an inability to enjoy penetrative sex to the mix, it's like pouring gasoline on a fire. One result, as you may know or can imagine, is all too often like the one Shelley experienced— the end of the relationship. The situation is just as complicated for those looking to begin relationships, as Claire learned: "I remember one man I started dating whom I really, really liked," she told us. "The issue of sex came up pretty quickly, so I told him about my 'problem.' He broke up with me that week."

In one study, 61 percent of women with vulvodynia reported that their condition affected how close they felt they could be with someone they loved, and 44 percent said it made showing affection difficult. Several studies also show that most or all aspects of sexual function (i.e., desire, arousal, and orgasm) and relationship satisfaction are negatively affected when you have vulvodynia. The thing is, no matter how much we try to focus on other aspects of a relationship, many people consider penetrative sex to be a crucial component. Study after study demonstrates that couples who have a satisfying sex life have happier, stronger relationships. Yet, as surveys find, eight in ten women with vulvodynia report that the pain "significantly and negatively" affects their sex lives. In one survey, nearly all the women with vulvodynia said they had stopped intercourse at least once because of pain, and more than half had simply stopped having sex. For some, the pain of sex had become so overwhelming that they didn't even want to masturbate or allow themselves to become aroused, whether or not doing so lead to sex.

Overall, studies find that women with genital pain are less likely to initiate sexual activity and more likely to refuse their partners' sexual advances. Clearly, this can't be good for a relationship. You

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probably have your own story about how this pain has affected your relationships and these studies show that you're not alone!

So, if sex is so important to a relationship, and you're unable to engage sexually because of the pain, does that mean you have to give up on having intimate relationships? Absolutely not! In this chapter, we describe how to maintain an intimate relationship as you work through the diagnosis and treatment of your pain, so you can, hopefully, emerge on the other side not only pain-free, but with the person you want to be with.

PAIN AND YOUR PARTNER

Which do you think would make your pain worse: (a) a partner who doesn't understand your pain and acts resentful, or (b) a partner who is understanding during sexual intercourse, giving your pain a lot of attention and saying kind things to make you feel better? Surprisingly, the answer is both!

We've known for years that in other chronic pain conditions, very understanding partners provide a kind of 'permission slip' for the person experiencing pain to give into it. They help their partner *avoid* the pain, making the pain bigger than it deserves to be. Thus, the person in pain focuses even more on the pain, starts reducing their activity level, and reports higher levels of pain. It turns out that the same thing is true with vulvodynia. In one study, those who perceived their partners as kind and understanding reported more intense pain than women whose partners had responses that promote adaptive coping.

Why? What's going on? Researchers speculate that sympathetic responses encourage the avoidance of sexual activity, reinforce perceptions of extreme pain, and may also contribute to "catastrophic thinking" about the pain. Catastrophic thinking

means perceiving something as exponentially worse than it really is. So, for instance, instead of thinking, "This burning really hurts, and I need a cool bath to make it feel better," a person may think, "The pain hurts so much and nothing can make it stop" or "I'll never be able to have sex again." Let's face it, most if not all people with severe pain will have catastrophic thoughts at some point. Unfortunately, they only make the situation worse.

If a partner's understanding can make you perceive your pain as more severe, why doesn't unsympathetic behavior make you perceive it as better? When a partner's response is resentful, it can contribute to depression, which increases pain among those suffering from provoked vestibulodynia. An

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The National Vulvodynia Association is a nonprofit organization that strives to improve women's quality of life through education, research funding, support and advocacy.

The NVA 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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unsympathetic partner is unlikely to explore new ways of being intimate that don't trigger pain. Plus, if you're not engaging in sexual activity, this type of partner is likely to make you feel guilty about it. All of the above can make you feel more anxious, which also intensifies pain.

What seems to work best is having a partner who engages in what researchers call *facilitative responses*. These are characterized by affection and encourage you to cope with the pain in an adaptive way, e.g., by suggesting that you use deep breathing or a cool sitz bath to help manage the pain. The partner in this situation teams up with you to confront the pain with helpful strategies, as opposed to rejecting you or colluding with you to avoid the pain (and sex).

THE PITFALLS OF CATASTROPHIC THOUGHTS

Catastrophic thinking interprets everything (the pain, the effects and limitations of the pain) as worse than they are and leads to feelings of hopelessness. Let's admit it— yes, the pain is bad, everything seems to be falling apart, and no one is able to help you right now. But does it mean that nothing will ever change for the better? That you will be stuck in this pain forever with no chance of being in a sexual relationship again? One reason that we wrote this book is to let you know that there can be an end to your pain— a future in which the pain is no longer a dominant part of your life.

Catastrophic thoughts happen, and they are to be expected when you have chronic pain. The challenge is to not let them become the dominant or only thoughts you have about your pain and your future. What can happen is that you start to believe these negative thoughts and only “see” information that reinforces them. When you are in this negative loop, you can even become resistant to accepting positive information from a vulvodynia specialist you haven't seen before.

THE PARTNER FALLOUT

Now that we've discussed how your partner can affect your pain, it's important to consider your pain's impact on your partner.

Fernanda, a single woman, said the worst part of her condition was the toll it took on her relationship. “You begin to dread intercourse, so your partner feels that you're not interested in him. But you don't want to abstain completely because then you no longer feel connected romantically.” She would often push herself to have sex, but when her partner saw how much pain she was in, he felt awful for being its trigger. “I just no longer felt like a normal woman who was capable of being loved,” she said.

There is no question that being involved with someone who has vulvodynia is a challenge. Some partners become very frustrated or feel helpless, angry, or depressed. Often, they simply don't understand what's going on. Maybe they think their partner is avoiding sex for other reasons and take it very personally. For example, they may think their partner doesn't find them attractive anymore and feel rejected. Even partners who understand what's going on may inadvertently contribute to relationship problems by avoiding any type of physical intimacy with you. In our experience, about 25 percent of these relationships are in pretty good shape, 50 percent are spiraling downward, but can still be rescued, and 25 percent are falling apart— often because of other reasons in addition to the pain.

That's probably why we see some relationships end even after the pain has improved. In these situations, the pain becomes a scapegoat for all the other issues in the relationship; once the pain is under control, the other issues remain, and the partnership doesn't recover. It's important that you try not to pin all your relationship problems on your pain.

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MOVING BEYOND PENETRATIVE SEXUAL ACTIVITY

If you're not engaging in sexual intercourse because of your pain, how can you maintain a strong relationship with your partner? By understanding that sexual intimacy is about much more than penetrative sex. It's also cuddling, stroking, and caressing non-painful areas. It's oral sex or masturbation with your partner or on your own. It's learning what type of intimacy each of you likes. It's remaining positive and hopeful that you will find effective treatment and be able to have the sexual relationship you want. Most of all, it's communicating, communicating, communicating.

Stephanie has been with the same partner since her pain began three years ago. Even though penetrative sex was one aspect of their sex life, they have managed to limit activities that lead to pain and get creative with aspects of their sexuality that they otherwise may not have explored. "We talked a lot at the beginning about how to navigate the pain. We then slowly started experimenting with different positions, kinds of touch, and sex toys, and we always kept our connection and pleasure as the main goal. We have never been more satisfied!"

Couples that have maintained a strong relationship say that communication and commitment is the key to success. This is corroborated by the research. Women with vulvar pain who are in relationships report that the pain affects their sexual and relationship adjustment less when there is a lot of communication and expressions of love. This usually involves being creative at finding sexual activities that are pleasurable for both partners. This requires sexual flexibility, the ability to navigate around sexual issues that come up instead of letting those issues "block" you from being sexual. Let's consider an analogous situation. When you are traveling by car and a route is closed off, do you begrudgingly give up your plans and return home in a frustrated mood, or do you

head off into the back roads and explore the scenery along the way?

Sexually flexible people are open to experimenting and aim for achievable goals that are pleasurable or fun. When one partner has vulvodynia, a flexible couple works together to redefine sexuality and explore new sexual activities. Research has shown that people who are sexually flexible are more sexually satisfied.

So what can you do to keep the sexual 'spark' alive? "I have a very loving, patient, and understanding husband of six years," says Lynn, forty-two. "I do not think any other man that has been in my life would have understood my pain like Bruce. I still feel like a woman with him, and I know I am okay!" Bruce makes Lynn feel this way by continuing to treat her as a sexy, beautiful woman. He compliments her on her body; he touches her often in places that don't lead to pain. He kisses her for no particular reason, sends her loving texts and keeps the romance alive in their relationship.

Below are some suggestions for maintaining sexual intimacy, but you and your partner should be able to come up with your own ideas.

1. Give each other massages. Set aside an hour, and if you have kids, lock your bedroom door. Agree up front that this will not lead to sexual intercourse. That way, you can relax and enjoy the experience. Don't worry if, as is expected, you or your partner become aroused. We'll get to what you can both do about that in a minute. Keep this time special.
2. Give each other permission to masturbate. Whether done alone or together, it can help relieve sexual tension and may relieve guilt about not being able to have sexual intercourse with your partner.
3. Bring your partner to orgasm. You can use your hands or your mouth or a sex toy— whatever works!

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Anesthetic Nerve Blocks for Severe Vulvodynia: A Pilot Study

A gynecology practice in Karlsruhe, Germany did an observational study of multiple anesthetic nerve blocks in women with severe vulvodynia. Their goal was to determine whether repeated anesthetic blocks could provide long-lasting pain relief in patients whose symptoms had not improved with prior vulvodynia treatments, including oral medications, pelvic floor muscle therapy, topical and injected steroids, topical hormones and acupuncture.

Subjects

All 45 participants fulfilled the ISSVD criteria for vulvodynia and had suffered from vulvar pain for a minimum of six months. None had comorbid conditions. All had previously sought help from an average of seven doctors and tried multimodal pain treatments. They reported pain levels of at least 6 on a 10 point scale, with a median pain score of 7.9.

Method

In this study, patients received between 3 and 12 treatment sessions depending on improvement in their symptoms. The injections contained 1% prilocaine, a local anesthetic with the greatest anti-inflammatory potential. The first three treatment sessions (one to three weeks apart) consisted of a perineal pudendal nerve blockade. The doctors chose this method because it is more comfortable for the patient than the intravaginal or transgluteal route. If symptoms persisted, further sessions targeted (i) the genitofemoral nerve via the inguinal

canal or (ii) the hypergastric plexus, which was accessed intravaginally.

Results

A successful outcome was defined as a pain score of 4 on a 10-point pain scale. A majority of patients (68 percent) experienced significant improvement after three sessions of perineal pudendal nerve blocks. Eighty percent of patients reported improvement after an additional two sessions, in which we administered a genitofemoral block (session 4) and a hypergastric plexus block (session 5). The average reported pain score of 80% of patients after three to five treatment sessions was 2.74/10. (The average pre-treatment score was 7.9/10.) The median follow-up period was 21 months, during which pain-relief was maintained.

Conclusion

Repeated anesthetic nerve blocks are a low-cost, easy-to-learn and effective treatment for vulvodynia patients who have not responded to other treatments. Furthermore, these injections targeting pelvic nerves did not produce adverse side effects. The substantial success rate of three pudendal blocks raises the question of whether some women with vulvodynia actually have pudendal neuralgia.

Source: Weinschenk S, Benrath J, Kessler E, et al. Therapy With Local Anesthetics to Treat Vulvodynia. A Pilot Study. *Sex Med* 2022;10:100482. ■

The Search for Effective Treatment

Researchers in many countries need funding to develop more effective treatments for vulvodynia. Over the past five years NVA has awarded pilot research grants totaling \$325,000. We have supported studies on the effectiveness of Botox, low level laser therapy and a less invasive vestibulectomy. To read about these studies, visit <https://www.nva.org/research/nva-medical-research-fund/>.

Currently, we have proposals from four researchers whose aim is to develop a novel treatment for vulvodynia. The number of studies NVA can fund depends entirely on the commitment of individual donors like you. Please make a tax-deductible donation at <https://www.nva.org/donate/> or mail a check, made payable to NVA, to Phyllis Mate, 9016 Rouen Lane, Potomac MD 20854. ■

Book Review

By Michelle Living, NVA Support Director

When Sex Hurts, 2nd edition, has been completely revised and updated to include the latest research on vulvodynia, pelvic pain and their impact on sexual relationships. Four vulvodynia/pelvic pain experts wrote this book for patients and the content is relevant to anyone who suffers from these painful conditions, regardless of whether she/he is sexually active. As a person who lives with vulvodynia, I found it empowering to have access to so much valuable information. Reading this book made me feel validated, because these authors clearly understand the pain I experience.

Among its many chapters, the authors cover the different types of pelvic pain, the diagnostic process, treatments that relieve pain, and how to redefine sexual intimacy. *When Sex Hurts* provides patients with tools to relieve their pain and maintain sexual intimacy. It is also an important book for health care providers that want to learn how to help patients with vulvodynia and related medical conditions.

What follows is an excerpt from the chapter on provoked vestibulodynia:

“...in general we have gotten much, much better at narrowing in on the causes of each individual person’s PVD/vulvodynia and can tailor a treatment plan made for them, and one that is much more likely than not to succeed. As we write this book, we believe we get 80 to 90 percent of our patients at least 80 to 90 percent better. Not perfect, but a huge improvement over what patients could expect only a few short years ago. The algorithm we have developed and continue to modify is the distillation of our diagnostic and treatment approach. We often refer to it as “our brains on paper.” When we use a hunch and deviate away from this algorithm, we are more often wrong than right.”

(Goldstein A, Pukall C, Goldstein I, et al. *When Sex Hurts: Understanding and Healing Pelvic Pain*. 2nd edition. Hachette Go. 2023.)■

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Just make it sensual and sexy. We guarantee it will be appreciated! You may even find yourself taking pleasure in watching your partner’s pleasure.

4. Have your partner bring you to orgasm in whatever way you like.

5. It is important to always have a backup plan. If an activity is not working, shift gears completely and try something else.

6. Foster connection in various ways. Find a hobby that you can learn together, book a date night and explore new places or activities - anything that will have you creating new experiences together.

7. Kiss, hug, snuggle, hold hands. A lot. Remember being a teenager and kissing for hours? And when we say hug, we mean holding each other so tightly you almost lose your breath. Showing physical affection is key to keeping the romance alive.

8. Text each other during the day, even if you are both home. These messages can be sexy and loving or kind and thoughtful.

We’ve seen couples who enjoy making lists of the things they love about each other that have nothing to do with sex. You can try this with your partner:

- Write down five things you love about each other that have nothing to do with sex.
- Keep this list close by so you can check it often.
- When either of you becomes totally frustrated with the situation, schedule a “reading of the list.”

Lastly, if you’re having difficulty in your relationship or would like more advice on making changes that foster intimacy, some sessions with a sex or couples therapist can help you get back on track.■

In Their Own Words

By Soph Myers-Kelley



When I was diagnosed with vulvodynia and hypertonic pelvic floor dysfunction, I was a cisgender woman. It rocked my entire world thinking how it could be harder to find a partner, have sex, work, travel, and wear tight clothing because of this new diagnosis. It was scary and I didn't want to face that truth. I cried in front of the doctor who diagnosed me, and she noted that in my patient records as if she were surprised someone would have that reaction to getting a painful diagnosis with no surefire cure.

Now, five years later, I've undergone many transformative journeys beyond those two first diagnoses. Part of that journey is coming to accept PVD and vulvodynia are parts of my life at this time. My pelvic pain is largely attributed to a condition called Ehlers-Danlos syndrome, which affects all of the collagen in my body. I've also found out I'm autistic and have ADHD. But one of the most significant discoveries has been recognizing I am not a cisgender woman, but a transgender, nonbinary being.

Going on testosterone, getting top surgery (having my breasts removed), changing my legal name, and changing up my hairstyle and clothing has brought a lot of joy and radiance to my world. Taking steps and seeing how it brings me closer to who I am and want to be is an honor to see and make happen. However, this has complicated my health journey, a journey that has already been too complicated for my liking.

On top of having multiple systemic conditions and chronic pain, I now think about whether my health care providers will correctly gender me. I don't use she/her pronouns anymore, sticking largely now to they/them and he/him pronouns. I wonder if I go to a women's health clinic for a gynecologic-related

appointment, will they assume I'm a woman just from walking in? Will they notice my deeper voice? Usually (since I'm only a year into my physical transition) they do not. I'm hopeful that in a few years' time on testosterone, that will change. Regardless, it frustrates me knowing that people like me will continue to struggle with having vulvodynia AND being misgendered, disrespected and isolated from spaces meant to be supportive. Spaces for vulvodynia havers, not just cisgender women.

As I continued in my transition, I had to leave more social media support groups that continued to use language that only included females, even after nonbinary and trans people respectfully took their time to explain why language change would make so many people's days. People even offered ideas for more inclusive language. The people who fought against inclusion made me realize I didn't need that kind of support, a support that didn't see and respect me for who I am.

Having a vulva does give me a bit of dysphoria from time to time (feeling an incongruence between my internal self and my external body) but it is made far worse when people assume who I am just because I have one. Over the years I have learned how to manage my vulvodynia and avoid triggers when possible. I've found beauty in low-crotch pants, working with a physical therapist, managing wider systemic pain and food sensitivities, and incorporating medications as well as naturopathic treatments like herbs into my care routine.

Some of my identities help make living with vulvodynia much easier, surprisingly. A beautiful thing about being polyamorous and queer is that, more often than not, queer partners are happy to have sex without penetration, be extremely consent forward when engaging in penetrative sex (i.e., happy

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to stop if it hurts and you say so), and more than happy to be close without being sexual at all! It's such a relief to know that the right partner(s) will value me for who I am, not what kind of sex acts I can or can't perform.

It's been a bumpy ride from being a cisgender, straight, monogamous, able-bodied, neurotypical woman to becoming a transmasculine, gender-queer, gay, neurodivergent, disabled medical librarian. At times the pain is completely unbearable, I understand. And yet because of it, I've found all of the disability gains in this beautiful, painful life of mine. I live and stand up for my name, my pain management needs, and the needs of my community in hopes that we will one day live in a better world.

By Paula R.



In my early twenties, I had my first urinary infection, after which I had at least one every year. The symptoms were burning and the need to urinate often, to the point it was waking me up at night. In 2018, I thought I had my

usual urinary infection, but my culture came back negative. I went to several doctors, all of whom gave me medication for a urinary infection I didn't have. Looking back, I don't blame my doctors for not looking further into it, because I also thought they were recurrent UTIs. Eventually I saw a doctor who acknowledged how unusual it is to have symptoms of an infection with a normal urine culture. He asked me, 'Have you noticed a change in your vaginal flux?' That's when I realized I had lost most, if not all, of my vaginal fluids! I am forever grateful to that doctor for sending me in the right direction. I saw an ob/gyn who was able to diagnose me, even though she didn't have experience treating vulvodynia patients. It was reassuring just to hear there was a word for my condition.

When my pain was most severe, I was in school and

Covid struck. My stress level was very high, which worsened the burning sensation and feelings of despair. I used ice packs and pain medication, but they didn't control the pain. I felt isolated even though I had a good health care team and support from my partner and best friend. Knowing I had a condition that didn't have a cure was difficult emotionally.

My gynecologist recommended that I see a physical therapist (PT) to assess and treat my pelvic floor muscles. A lovely PT taught me coping strategies, such as deep breathing and meditation, that helped to bring the pain down to a 3 out of 10. I even have some pain-free days now. Two years ago, I couldn't even imagine having days without pain.

This entire experience taught me not to assume that pain will be permanent and that I can make it through the difficult days. I learned to accept that there will be not-so-good as well as good days. My advice to other women with vulvodynia is to keep searching until you find the care you need. Equally important, all of us need to understand that having vulvodynia does not define us. ■

NVA Referral List Available Online

The NVA maintains an extensive list of health care providers skilled in the diagnosis and treatment of vulvodynia. If you need a doctor, nurse practitioner, physical therapist or sex therapist, visit our website at: www.nva.org/providers. There, you can either view the entire list of providers in the US or you can perform a zip code search.

Please help us keep this list up-to-date by letting us know if you've had a positive (or negative) experience with a particular provider. If you want to recommend someone who is not on our referral list or if you discover that a provider has moved or retired, please email their name and contact information to lisa@nva.org.