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NVA News

Volume I, Issue 4 Winter 1996

Diagnosis and Management of Vulvodynia

Questions and Answers with Gae Rodke, M.D.

Dr. Rodke is clinical assistant attending physician, Department of Obstetrics and Gynecology, at St. Luke's Roosevelt Hospital Center in New York City. She has worked extensively with vulvodynia patients in her private practice, and recently co-authored a study on the use of biofeedback for the treatment of vulvar vestibulitis.

NVA: Is vulvodynia a difficult disorder to treat?
GR: I think it's probably the most difficult and challenging condition that I treat. The problem with vulvodynia is that its origins are poorly understood and its treatments are largely empirical (trial and error). Patients experience all the difficulties of a chronic pain syndrome, without the assurance of knowing the cause of their pain, or that the treatment is defined and relief is predictable. Also, the treatment time frame is frustrating for everyone involved. Most effective vulvodynia treatments take a minimum of six to eight weeks to begin working well, and supporting a patient through that period, not knowing if that particular treatment will be effective, involves a lot of time and emotional energy. On the other hand, when patients do improve, I don't think there's anything more rewarding. In addition to relieving pain, you are restoring a woman's ability to enjoy sexual relations.

NVA: What do you look for when you see a new patient with chronic burning and pain of the vulva?
GR: I look for clues in her history that might point to the initial instigating factor. On physical exam, we look for any ongoing exacerbating problems of infection or abnormalities of the vulvar skin. Doing a very thorough evaluation helps me to choose an intervention that's most likely to give the patient some relief.

NVA: When evaluating a vulvodynia patient, is it important to look at her vaginal flora under a microscope?
GR: I think it's crucial. A lot of women think that anything that itches or burns in the vaginal area is a yeast infection. But at least half of the women who think that they have chronic yeast infections are wrong. While some do have chronic cyclic candidiasis, others either have another form of vaginitis or vulvodynia. Also, some women don't have a good understanding of the interrelationship of the urinary and vaginal tracts. The urethra, bladder and vagina are very close to each other, and the common innervation of this area can cause neurological signals to get mixed, resulting in confusion about where a symptom originates. So I think that without actually looking under the microscope, you can't really decide how much of a role vaginal flora play in the symptoms a patient is having.

NVA: Some women with vulvodynia experience cyclical flare-ups in their symptoms. Can changes in the vaginal flora cause such flare-ups?
GR: There are hormonal changes in the cycle that tend to favor different subgroups of the vaginal flora. When certain bacteria encounter alkaline conditions, such as cervical mucus at ovulation, semen after intercourse, or

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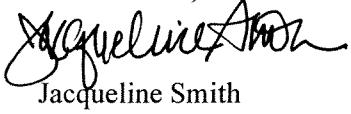
INSIDE

Letter from the Executive Director

As I write this, one of my most cherished friends is in the hospital waging battle with an illness that has plagued her for more than a decade. She suffers from rheumatoid arthritis, in its most severe form. It has left no part of her body untouched.

Over the years, I have watched, with great admiration, her remarkable ability to live life on her terms, never letting the devastating pain destroy the essence of her life. Grandmother to my children, she has given them a heroine to worship. She faces the worst of fates, yet finds the inner strength to overcome it, so that she can cherish us and embrace life.

In my time as executive director of the NVA, I have spoken with thousands of women who live with pain every day. I would like to dedicate this first year anniversary issue to my courageous mother-in-law, Jean Fraser Smith, and to all of you who cope with chronic pain.



Jacqueline Smith

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blood with menses, they emit chemical compounds called amines; these compounds produce a fishy odor and can result in burning and discomfort during ovulation or menses. The increase in progesterone just before menses can cause an overgrowth of bacteria, resulting in an abundance of lactobacilli at this time. And sometimes, if a woman is prone to chronic yeast, a flare may occur right after menstruation, because blood is a wonderful growth medium for yeast as well as bacteria. All of these factors can cause a latent infection to become more symptomatic at some point of the cycle. Also, estrogen levels are at their lowest right after menstruation, causing the vagina to be a little drier and more irritable at that time, especially in women over the age of 35.

NVA: What are lactobacilli, and why is overgrowth a problem?
GR: Lactobacilli are "good" bacteria which normally live in the vagina. They are sugar-eating organisms that multiply as the vaginal secretions become more alkaline. As they multiply, they secrete a mild acid which restores the acid balance to the vagina. However, if the lactobacilli overgrow, the vaginal secretions become too acidic, and can produce vulvo-vaginal burning and itching.

NVA: If there is an overgrowth of lactobacilli, what can be done to correct it?
GR: If this is the problem, often a series of baking soda and water douches (one tablespoon per quart of tepid water), every other day during the week before menses, will alkalinize the vagina somewhat. They will also reduce the volume of irritating discharge to a more tolerable level. For some women, performing this regimen for one or two cycles in a row, will return their flora to a more balanced state. If this method doesn't help, women who have a persistent overgrowth of anaerobic lactobacilli or symptomatic lactobacilli can use doxycycline, an antibiotic. But antibiotics increase the risk of yeast overgrowth, so this method can create further complications.

NVA: What is usually your first line of treatment for vulvodynia patients?
GR: It depends on the patient's history and major symptoms. First, I make sure there is no vaginitis present. Then, if the patient's main symptom is burning pain, I will often start with a tiny dose of a tricyclic antidepressant, since those drugs are considered useful in treating burning pain in other areas of the body. If, on the other hand, she's had a history of yeast infections, tends to be an allergic person, and/or I see signs that she may have very reactive skin, I often start with an antihistamine instead, in order to stabilize the histamine packets in the white blood cells. In addition to the tricyclic or the antihistamine, I generally have patients apply cold compresses several times a day, using either plain water or Aveeno

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colloidal oatmeal solution. The patient can mix two tablespoons of Aveeno with a quart of cold water and apply it with a cotton ball, keeping the remainder in the refrigerator. Many of my patients find this very soothing. I also recommend increasing fluid intake, decreasing very high oxalate foods in the diet, rinsing off after urinating, and avoiding all allergens or irritants that the patient may have been using on the vulva. Finally, I mention the role of biofeedback in treating this condition.

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NVA: Many people complain of side effects from the antidepressants. Do any of the side effects subside?
GR: The three side effects patients complain of most frequently with the antidepressants are fatigue, dryness and constipation. Initially, the patient might feel tired and lightheaded all day. However, this feeling generally resolves after a week or two, when the body becomes used to the drug. If the patient tends to be an early morning person, I recommend that she try to take her medication a little earlier in the evening, so that the level in her body has fallen below peak by the time she needs to start her day.

The dryness might diminish somewhat, but is usually an ongoing problem. Drinking a lot of fluids can be helpful. For those who are able to have sexual intercourse, I generally recommend extra lubrication to decrease friction on the tender skin. If one is already prone to constipation, it will continue to be a problem. Ongoing measures to decrease constipation, primarily bulk-forming laxatives such as Metamucil, Citracel or bran, will help. These laxatives must be taken with a lot of water, because otherwise they tend to make the stool more solid.

NVA: How long do you pursue each treatment before determining whether or not it will help the patient?
GR: I like to make sure that a patient has achieved an adequate dosage level, and that she's been at that level for a good six to eight weeks before I decide that a particular drug isn't helpful. In the meantime, I may well have added another agent to the regimen. Once the patient is comfortable, I like to continue that therapy for a minimum of three to six months, and then gradually taper down, one part of the regimen at a time. The goal is to totally wean the patient off all therapy. If this is not possible, we can determine which therapy we need to continue, at what level. Many patients are able to successfully wean from all medications, and others end up taking a much smaller dose of one medication on an ongoing basis.

"Most effective vulvodynia treatments take a minimum of six to eight weeks to begin working well..."

NVA: You were a co-author, with Howard Glazer, Ph.D., of a study involving the use of EMG biofeedback on the pelvic floor muscles

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as a treatment for vulvar vestibulitis.[1] Can you explain how this treatment works?

GR: Often, by the time I see a patient for the first time, it has been several years since her symptoms began, she has had many treatments, and the initiating factor is no longer present. The premise of the biofeedback study is that some patients have a predisposition to develop a sympathetically maintained pain syndrome; some factor instigates the pain initially, and this pain causes a reflex spasm. This spasm increases the stimulation to nerves coursing through the area. The increased nerve activity travels to the level of the spinal cord, amplifying any additional messages coming into the spinal cord and producing more pain. Antedromic activity that causes dilation of the blood vessels, inflammation, and subsequent release of histamines to the area can also occur. As a result, the skin becomes more tender, any subsequent touch or insult is amplified, and the cycle of pain, spasm and reaction begins again. Consequently, we thought if we could interrupt this cycle at any point, it would help the patient improve faster.

The pelvic floor muscles are a group of muscles that encompass the entire pelvic area, from the pubic bone in the front to the coccyx bone in the back. They include the urethral and anal sphincters. The biofeedback exercises aim to rehabilitate and strengthen the dysfunctional pelvic floor muscles, thus relieving any tension and spasm, and breaking the cycle of chronic vulvar pain.

NVA: And what were the results of the study?

GR: On baseline assessment, the vulvodynia patients in the study exhibited instability and weakness of pelvic floor muscles. The muscles didn't function in an organized fashion, probably as a result of prolonged pain and spasm. The subjects' contractions were brief and less effectual, the baseline resting tone was often elevated and the stability of the muscles at rest was significantly impaired. Treatment resulted in muscle stabilization, increased strength and better muscle relaxation. Once the muscles were rehabilitated, many of these patients became pain-free and were able to engage successfully in sexual intercourse.

> "The biofeedback exercises aim to rehabilitate and strengthen the dysfunctional pelvic floor muscles, ... breaking the cycle of chronic vulvar pain."

NVA: What does the treatment involve?

GR: The treatment starts with an assessment. The patient places a sensor approximately the size of a tampon into the vagina, in privacy, and remains fully clothed. A wire runs from the sensor and plugs into a computer. While the patient contracts and relaxes the muscles, the computer draws a graph which shows us the strength, relaxation level, and stability of those muscles. If the evaluation reveals pelvic floor muscle dysfunction, the patient is taught exercises to rehabilitate the muscles. She rents a home perineometer for use with her sensor, which helps her to assess whether she is doing the exercises correctly. We advise the patient to exercise for twenty minutes, twice daily, until she achieves symptom relief. We evaluate her intermittently over that period, with decreasing frequency as she becomes more skilled.

NVA: When do you suggest evaluation for pelvic floor muscle dysfunction?

GR: I generally mention it to all vulvodynia or vulvar vestibulitis patients at the first visit, because right now it seems to have the highest success rate of any of the treatment modalities that I use. However, because of the time commitment involved and vulvodynia patients' resistance to inserting anything vaginally, they are often initially reluctant to do the evaluation and follow the therapy. So I usually try simpler,

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more remote methods of treatment that don't involve direct contact with the vulva first, and then once a patient is feeling slightly better, I again suggest that she have a biofeedback evaluation.

NVA: What other alternative or non-medical treatments do you recommend to your patients?
GR: I think that approximately one-third of my patients are helped by following the low oxalate diet, as described by Clive Solomons, Ph.D. I advise patients to avoid the high oxalate foods and rinse the vulva after voiding. One can also reduce the concentration of oxalates in the urine by increasing fluid intake. There was an interesting paper presented at the most recent ISSVD meeting that suggests that women with vulvodynia may not have higher levels of oxalate than women without vulvodynia, but may just be more sensitive to oxalates. Or, it may not be oxalates themselves that cause pain; they may just be a marker for concentrated urine, or for an increased concentration of other irritating solids in the urine.

NVA: Do you advise patients to take calcium citrate in conjunction with the low oxalate diet?
GR: Calcium citrate is the best absorbed form of calcium, and I think that all women in their 30s and beyond should increase their calcium intake for osteoporosis prevention anyway. When Dr. Solomons' patients receive the results of their oxalate tests, they also receive information on the low oxalate diet and a recommendation about taking calcium citrate. I have no objection to patients taking reasonable quantities of calcium citrate. I think that the potential for harm is small, and there are studies showing that the concerns about renal stones from calcium intake are unfounded.

NVA: Can physical therapy play a role in the treatment of vulvodynia?
GR: Absolutely. In addition to biofeedback, there are other modalities, such as massage of tender trigger points, that can be helpful. I think that this concept is difficult for some patients and practitioners to accept, but for patients who are open to the idea, I think that there is a chance for them to feel better, sooner. But given that this could involve massage of the pelvic floor and the vaginal entrance, I think it is important to ensure that the physical therapist is reputable and specifically trained in these techniques before beginning treatment.

NVA: Some doctors are prescribing the use of topical estrogen for vulvodynia, even though no published research has validated this practice. Do you ever recommend this treatment?
GR: I have used topical estrogen for this condition. I was quite intrigued by the description of its success by Dr. John Willems, a gynecologist at the Scripps Clinic of La Jolla, California. I find it especially helpful in women who are beyond their mid-thirties, when the vestibular glands tend to produce less lubrication. I also find it helpful for patients whose vaginal smears reveal a low estrogen effect when examined under the microscope. I wish to emphasize that the amount used is very small. We are not prescribing full, post-menopausal estrogen doses that are used for atrophic vaginitis. Vulvodynia patients use a tiny dab of estrogen cream on a daily basis, applying it topically at the level of the hymenal ring, just at and inside the introitus. Such a small quantity is very unlikely to cause any major systemic complications.

NVA: Have you seen any success with estrogen?
GR: I have had patients who have become significantly more comfortable with the use of estrogen. Women who do not have ongoing burning pain, but only focal vestibular tenderness, and whose main presentation is painful intercourse or tightness and dryness at the vaginal opening, seem to have the most success.

NVA: If a vulvodynia patient has a vaginal infection (yeast or bacterial) but has been sensitive to vaginal suppositories in the past, what are her best treatment options?
GR: For these patients there are various oral agents which are successful in treating most cases of vaginitis. Another alternative is to find a pharmacist who does compounding, and have him/her mix the active ingredient into an

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Empower Yourself

Establishing Doctor/Patient Relationships

Most women with vulvodynia have had frustrating experiences with one or more doctors at some point. Vulvodynia sufferers usually see five or more physicians before receiving an accurate diagnosis and appropriate treatment. Many have felt the embarrassment and self-doubt caused by physicians who claim that there is nothing wrong with them, or even worse, that their symptoms are psychological. Even when they find a doctor who treats vulvodynia, many patients are unsatisfied with the relationship. For example, many patients feel that they are at the mercy of the doctor, talked down to, ignored, or lack input into their own medical treatment. Yet most people who suffer from difficult-to-treat or chronic disorders will agree that the quality of interaction with their doctor is extremely important. And many vulvodynia patients have found that establishing a positive rapport with a caring and knowledgeable physician is essential to their emotional and physical well-being. Consequently, this article describes what you can do to promote an effective and satisfying relationship with your physician.

It is often difficult to find a doctor who knows something about vulvodynia and is willing to treat it. However, some doctors who are unfamiliar with the disorder may be willing to learn more about it and work with you. Ask your doctor if he/she will read medical journal articles on the subject, and is open to receiving information from you. Among other things, you can contact the NVA and ask that its newsletter be sent directly to your doctor's office.

> "With a disorder like vulvodynia, which has no simple cure, the doctor and patient need to work as a team."

When interacting with a doctor, whether it is your first visit or an ongoing relationship, there are a few things to keep in mind. Although chronic vulvar pain can wreak emotional havoc on the sufferer, it is important to remain calm when describing your situation. If you become too upset or overwrought, the doctor may have trouble understanding you or you may fail to communicate valuable information. Even worse, some doctors might decide that you are an "overly emotional" patient and unfairly dismiss your problem as psychological. Keep in mind that telling your doctor in detail how your vulvar pain is ruining your life does not convey much useful medical information. Instead, consider preparing for your appointment by writing down points which are pertinent to your treatment, such as the chronological development of your problem, specific symptoms, and when they occur. In addition, list the names of medications you have used, their effect, associated problems, and any questions you want to ask. Copies of your medical records and recent laboratory or test results will also be helpful to have on hand.

With a disorder like vulvodynia, which has no simple cure, the doctor and patient need to work as a team. The first element in this partnership must be mutual respect. The doctor should respect your right to understand your treatment and ask questions. If your physician is not receptive to your concerns and discourages you from learning about your disorder, it is your prerogative to find another physician. At the same time, you should respect that the doctor did not cause your pain, and that it is not fair, or productive, to make him/her the focal point of your frustration and anger. Most physicians who treat vulvodynia are doing their best to help you; becoming angry at the doctor because you are not feeling better will only strain your relationship.

Good communication between you and your physician is obviously

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important. You should make sure that you understand all the doctor's instructions. If you are unsure of the effects of a particular treatment, you should ask questions until you are comfortable with it. You also have a right to refuse a treatment. But remember, if you refuse every regimen that is suggested, the doctor's ability to help you is going to be limited. Once you agree to try a particular approach, you must follow the doctor's instructions. If you experience a problem with a prescribed treatment, inform the physician and discuss whether you should discontinue or change it. If you modify the treatment yourself, then you cannot hold the doctor responsible when you do not improve.

Doctors who specialize in vulvar disease are usually overloaded with patients. This sometimes leads to difficulty in getting them on the phone when necessary. If this is the case, there are a few strategies you can follow. Start by asking your doctor during an office visit to tell you the best way or time to get in touch. It also helps to be courteous with the nurse or office manager who handles phone calls, since she can often find out the answer to your question and relay it to you. When dealing with a busy physician, it is wise to leave a detailed description of the problem that requires attention. This enables the doctor to prepare an answer in advance and make a quick call when there is a free minute. If your symptoms change or you think that you have an infection, the best approach is to make an appointment. If you can't get a quick appointment, explain your problem to the receptionist and ask if you can be squeezed in.

If your treating physician is a gynecologist, you should keep in mind that gynecologists are not generally prepared to handle chronic pain patients. Treating a woman with vulvodynia is a far cry from seeing a typical gynecological patient who comes in for an annual pap smear or an easily curable yeast infection. Dealing with the physical and mental anguish of chronic pain sufferers can be emotionally difficult for doctors, especially if they lack training in this area.

"If you are unsure of the effects of a treatment, you should ask questions until you are comfortable with it."

Hopefully, your doctor will respond to your efforts to form a partnership in your medical care, and your relationship will be characterized by mutual trust, understanding and respect. If you can create a balanced dialogue with your physician, you will gain a sense of control over your medical treatment. This will enable you to participate in making decisions about your care and carry out recommendations with a sense of confidence.

If you are an NVA contributor, there are past issues of the NVA newsletter available to you. Each edition features an interview with a physician who is experienced in the treatment of vulvodynia.

Vol. 1, Issue 1: Dr. Stanley Marinoff
Vol. 1, Issue 2: Dr. David Foster
Vol. 1, Issue 3: Dr. Helene Emsellem

If you would like to receive any of these issues, please write to the NVA office and enclose a check for $5.00 each.

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additive-free base. These preparations are not found on store shelves because they lack preservatives and can't be kept for a long time. They have to be mixed fresh and often refrigerated during the period of use.

NVA: Most vulvodynia sufferers find sexual intercourse painful. What do you suggest to these patients?
GR: I generally recommend that they try to maintain levels of communication and other kinds of intimacy in their relationship, outside of intercourse. I suggest they explore ways of pleasuring one another that don't involve a lot of direct vaginal friction. In addition, some women who only have focal tenderness at the vestibule do well with topical xylocaine. I use it in a solution rather than an ointment, because an ointment is more likely to transfer onto the partner, decrease his level of stimulation, and increase the amount of time it takes him to achieve orgasm. Such a situation can be inordinately difficult for a patient with vulvar pain. I prescribe the use of 4% xylocaine solution on a cotton ball, placed right at the introitus, for a period of five or ten minutes before intercourse. I also recommend they use a lot of lubrication. After intercourse patients should put a cold compress on the area, so that any reflex redness or swelling is suppressed before it can become a vicious cycle.

NVA: Are there any lubricants that you recommend, and any that should be avoided?
GR: I tell my patients to look for the lubricants with the least preservatives. I like Astroglide because it is water soluble, a very small quantity creates a good deal of slipperiness, and it doesn't tend to get gummy and gritty. Almond oil has similar advantages, although it should be avoided if one is allergic to nuts. Also, one should never use petroleum or oil-based lubricants when using latex condoms. I recommend either lambskin condoms or the new polyethylene condoms, if one is going to apply an oil-based product. I certainly don't advise the use of commercial cold creams or other products that have perfumes in them. Many of my patients are also sensitized to spermicidal products and must avoid them.

"publication of research enhances the knowledge of physicians... so that women are more likely to receive early diagnosis and prompt treatment."

NVA: Many vulvodynia sufferers are of childbearing age. What do you suggest to women who want to become pregnant, but find frequent sexual relations difficult?
GR: It is certainly useful to chart the woman's cycle and time intercourse to ovulation. If the patient cannot tolerate intercourse, she can manually stimulate her partner almost to the point of orgasm, and then the partner can ejaculate at the introitus, allowing the sperm to enter the vagina without full penile penetration. The woman can then lie on her back with her knees up, which will help the sperm to travel up into the vagina and the vaginal pool near the cervix. Alternatively, the couple can place the ejaculate into a diaphragm that has can then insert the diaphragm into the vagina without spilling the semen, and achieve pregnancy in that way. Another option is to place the semen in an unused eye dropper or turkey baster and insert the tip into the vagina. Obviously, we can also do inseminations in the office, but many women don't need that.

NVA: Is it difficult to do studies of vulvodynia treatments?
GR: Yes it is. Part of the problem is that patients are desperate to feel better. Traditional double blind studies require that one group receive an active drug, and another group receive a placebo

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Reader to Reader

Question: *When you're having a particularly uncomfortable day from vulvodynia, what home remedies make you feel better?*

As long as I have vulvodynia, it will be necessary for me to take special care of myself. I am the only one who can do this. There are three things that have eased my life: a foam rubber ring, rinsing the vulva after urinating, and cold packs. None of these will cure me, but they make my day to day life more comfortable.

The foam ring can be purchased for about $12.00 in almost any surgical supply store or pharmacy that sells medical equipment. I made a cover for my ring with some scrap curtain material and it looks like an ordinary seat cushion to other people. The design of the rubber ring enables me to sit in an anatomically correct position but takes pressure off the vulva. In this way I avoid the back pain that results from sitting off balance. I've learned to take my cushion with me almost everywhere.

Rinsing the vulva with cool tap water after urinating is another self-help measure that I follow all the time. I keep a small plastic container filled with water on top of the toilet tank in my house (Don't use a drinking glass because it could transmit organisms to the vulva). When I'm away from home I carry a small squirt bottle in my purse which I either fill at home or in the restroom. I also prefer to carry my own soft, unscented bathroom tissue.

Cold packs have been a real lifesaver for me. I discovered their benefits even before I received a diagnosis of vulvodynia. After some experimentation I found that the small blue gel packs (sized for lunch boxes) were ideal. I wash the cold pack with soap and water, place it in a clean plastic sandwich bag, and freeze it. When I have burning pain, I take the clean cold pack out of the plastic bag, wrap it in a clean terry washcloth or hand towel, and apply it to the vulva. This has also helped me after sexual intercourse.

In my experience, pain relief is valuable even if it is only temporary. It helps me relax and regroup. I try to plan a period of rest and comfort every day and I look forward to it. I set aside at least 30 minutes to lie down, read a good book, listen to music and apply the cold pack. It helps me cope with the rest of my day.

Next issue's question: *Vulvodynia patients often go through a series of treatment regimens before they find one that works. How and when do you decide whether a certain treatment is working for you?* (Please address your replies to Phyllis Mate, Newsletter Editor, P.O. Box 19288, Sarasota, FL 34276)

Moving?

To continue to receive your newsletter and to ensure that you are kept informed of NVA activities, please send your change of address to the NVA, P.O. Box 19288, Sarasota, FL 19288.

The NVA gratefully acknowledges the generous contribution of Sheila and Thomas Moore. A special thank you to Sheila for her efforts to raise political and community awareness of vulvodynia.

Vulvodynia in the Workplace

Part II: Telling Your Employer

In part one of this series (see Volume 1, Issue No. 3), the issue of whether to tell your employer and co-workers that you have vulvodynia was considered. It was suggested that you conduct research on your company's policies toward disability, leaves of absence, job-sharing and other alternatives. You were also encouraged to evaluate the consequences of revealing your illness.

If you have finally decided to talk with your employer about your illness, here are some ideas on how to proceed.

1. Choose the right time. Be sure that you have enough time and a private office in which to have your discussion. Inform your supervisor that you need about 30 minutes to discuss a personal issue. It is probably better to choose a Friday so that he/she can think about it over the weekend. This may also reduce the likelihood that it will be shared with curious colleagues. If you have a new boss, you must decide whether to bring up the issue right away or wait until you have proven yourself and developed a relationship.

2. Ask for confidentiality. Don't be surprised, however, if your boss is required to inform his/her superior or the human resources department. If so, agree on how it will be presented to anyone else.

3. 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 illness which is more manageable on some days than others. Assure your supervisor that you are doing everything you can to seek proper treatment. Depending upon the reaction, this may be a good time to request special consideration such as switching to flex-time or job-sharing.

"If you have a new boss, you must decide whether to bring up the issue right away or wait until you have proven yourself and developed a relationship.."

4. You don't have to be specific about your diagnosis. Most women are too embarrassed to reveal that they suffer from chronic burning of the vulva. Some women simply say that they have chronic nerve pain. If pushed for more information, a phrase like, "I'm just learning about it myself," should terminate the inquiry.

5. As with any sales pitch, practice is essential. Role play with a friend or family member first. Michelle, a member of the NVA, recalls how she told her supervisor about her condition without giving any details. He had never been ill himself, but was extremely concerned and willing to accept her idea for a job-sharing arrangement. "He was sympathetic and continues to be understanding," said Michelle.

Part three in this series: Employment options—which ones are right for you?

For those participants who suffer from Lichen Planus or Lichen Sclerosus, write to Harriet O'Connor at the NVA (P.O. Box 19288, Sarasota, FL 34276) for information on these disorders.

Book Review

Just Another Women's Problem:
Son recounts mother's battle with vulvodynia

Just Another Women's Problem is a tragic, personal account of the suffering and eventual suicide of Yvonne Wallis, an Englishwoman who coped with severe vulvar pain for 18 months before taking her own life. This short book, written by her son Mark Wallis, provides insight to a vulvodynia patient's loved ones and to medical practitioners who do not understand the severity of vulvar pain. Expanded by Yvonne Wallis' poems, this is a powerful tale of a woman's struggle with vulvodynia.

Only 47 years old when her agonizing pain began, Yvonne attributed the onset to a gynecological cream prescribed for vaginal yeast. She was told that she had experienced a severe reaction to the cream and that the pain would subside in five days. When her agony continued, she demanded to be seen by specialists, a costly option in England. In her search for an answer, Yvonne endured painful physical examinations, sleepless nights, lack of mobility, and a steady diet of painkillers and sleeping pills. Her son writes, "She would hold my arms, crying and saying that she could not take any more and that no one was helping her. When I would hold her I felt her whole body twitch with pain."

Even though her family was very supportive, she lacked a support network of fellow sufferers. Her rural English family did not have access to medical libraries and computer systems to research vulvodynia themselves. In reaction to her death, Mark Wallis and his father Bryan have been working hard to create greater awareness of this disorder in England.

Copies of this book are available by sending $10 U.S. currency to Bryan Wallis, 17 Rieburn Avenue, Dartford, Kent, DA1#BQ, England (please write legibly).

[**Editorial Note:** *Just Another Women's Problem* serves as a reminder that vulvodynia is a chronic pain syndrome that can cause serious depression and suicidal thoughts. Not all medical practitioners are trained to note signs of depression, so patients may have to recognize symptoms in themselves. Don't be embarrassed or afraid to seek help. If you are depressed, talk to a close friend or a family member. You can also ask your doctor for a referral to a health care professional who is experienced in treating depression resulting from chronic pain.]

Rodke (From P.8)

with no active ingredients. It's not easy to convince someone who wants to get better now to participate in such a study. A second reason is that in order to help patients improve faster, physicians will often start more than one therapy at a time, making it hard to ascribe any improvement to a specific component of that regimen. It's difficult to ask someone who's having so much discomfort not to use additional measures to reduce the pain. The third reason these studies are problematic is that patients naturally have some waxing and waning of their symptoms, and some patients spontaneously improve, which means that the timing of the assessment can significantly affect the results.

NVA: Nevertheless, is it important to do research studies of vulvodynia treatments?
GR: Yes, it is extremely valuable. Well-designed research studies legitimize both the condition and the treatments used. They are helpful in convincing insurers to pay for treatment. Most importantly, publication of research enhances the knowledge of physicians and other healthcare providers, so that women are more likely to receive early diagnosis and prompt treatment, shortening the time before they are physically comfortable and sexually functional again.

[1]Glazer, H.I., Rodke, G., Swencionis, C., Hertz, R., & Young, A.W. (1995). The treatment of vular vestibulitis syndrome by electromyographic biofeedback of pelvic floor musculature. Journal of Reproductive Medicine. 40, 283-90.

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