Vulvodynia is a medical term that means "painful vulva". The term can cover a wide variety of vulvar pain syndromes, including various infections and skin disorders.

* New in this edition:

1. Internet Vulvodynia Links;
2. Pregnancy and Vulvar Pain;
3. Finding a physician who can treat vulvodynia;
4. New treatments for neurologic vulvodynia, including capsaicin, carbamazepine (Tegretol), and neurotonin;
5. updated references.

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1. What are vulvodynia and Vulvar Vestibulitis Syndrome?
Vulvodynia is a medical term that means "painful vulva". The term can cover a wide variety of vulvar pain syndromes, including various infections and skin disorders. Vulvar pain syndromes have been written about in medical books since at least the late 1800s. In 1889, Dr. A.J.C. Skene wrote a "Treatise on the Diseases of Women" wherein he described a disorder that was characterized by an "excessive sensitivity" of the vulva. He stated that itching was absent, but when "the examining finger comes in contact with the hyperesthetic part, the patient complains of pain which is sometimes so great as to cause her to cry out". He treated this condition by surgically removing the affected area. However, he noted that this provided only temporary relief. In 1928, Dr. H.A. Kelly wrote about a condition characterized by "exquisitely sensitive deep-red spots on the mucosa of the hymenal ring" as a frequent source of painful intercourse. However, this condition appears to have then been ignored in medical journals until the early 1980s, when Dr. Edward Friedrich began reporting on it. Since 1983, more than 80 studies have been reported in the medical literature. It is unclear whether this is because this illness is increasing in incidence, or whether physicians are now simply recognizing the symptoms of vulvodynia in their patients due to being better informed. It's possible that both things are happening together. Today, the term "vulvodynia" is frequently used to refer to two conditions:

Vulvar Vestibulitis Syndrome: (VVS)
VVS is an inflammation of the vestibule, or opening to the vagina and the tissues immediately
around the vaginal opening. This condition is also sometimes called "vestibular adenitis". The classic description of VVS involves redness of the vulvar vestibule, especially with small red spots; pain with intercourse or tampon insertion and stinging pain when urinating.

**Vulvodynia of neurologic origin:**

This is also called "essential vulvodynia", "pudendal neuralgia" or "dysthetic vulvodynia". The classic description of pudendal neuralgia involves a more or less constant itching or tingling sensation in the vulva, ranging from mild to excruciating pain of the entire vulva. Pudendal neuralgia is probably due to compression or degeneration of the pudendal nerve, one of the main nerves that relays sensation to and from the genitals. This condition can also result from a spinal injury, or a tumor or cyst in the spine. Trauma during childbirth can also cause vulvodynia. In many cases, the exact cause remains unknown.

Israeli researchers suggest there is another subdivision of vulvodynia: vestibulodynia. They believe that vestibulodynia is a unique syndrome that affects women who are older than those who have vestibulitis alone and is associated with the presence of human papillomavirus (HPV), painful urination, and a higher failure rate for surgical treatment than that for vestibulitis. However, this subdivision is not universally accepted among researchers or treating physicians.

Also complicating terminology is the fact that it is possible to have neurologic pain of the vestibule, and for a problem which began as an inflammation (VVS) to turn into a long standing pain disorder with nerve involvement. Because of this, some physicians regard the division between VVS and "essential vulvodynia" as artificial and arbitrary. They think that vulvodynia should be classified as a subset of urinary and genital pain disorders or "painful bladder" syndromes. These syndromes include vulvodynia, urethral syndrome, interstitial cystitis, prostatitis and prostadyinia.

Vestibulitis and essential vulvodynia often occur in combination with inflammatory problems of the urinary tract such as interstitial cystitis or urethral syndrome. This is not surprising, since the lining of both vagina and bladder arise from the same tissue during fetal development; thus when one becomes inflamed, the inflammation may spread easily to the adjoining areas. Certainly, it is obvious even to the untrained observer that there is no line demarcating the urethral tissues from the inner lips of the vulva or from the vaginal lining, perineum and mucous membranes of the rectum.

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2. **What are the signs of vulvodynia?**

Vulvodynia can range from mild to severe. Usually, a burning or stinging sensation is noted during intercourse or when tampons are inserted; upon touching the area with a cotton swab, pain is felt when the hymen and inner vaginal lips are touched. There may or may not be visible redness and swelling. With vulvodynia of neurologic origin, the pain tends to be more or less constant and more diffused in area. In severe cases, the pain can be agonizing. The clitoris can become involved, becoming painful or hypersensitive and there may shooting pains from the clitoris up the abdomen. With severe VVS, much of the vulva can be reddened, swollen and very inflamed. Often, there is hypersensitivity along the edges of the inner vaginal lips and the pain can be so severe that it makes walking difficult. A constant itching or stinging sensation in the grooves between the large and small vaginal lips is commonly reported; some women cannot stand to wear underwear for this reason, because the slightest touch to the area results in excruciating pain. Other signs include pain or discomfort upon touching the pubic hair; a feeling of pain or discomfort all over the vulva; sensations of "parchedness" or drying, and "drawing" sensations, either all over the vulvar skin or only in certain spots. These sensations may extend to the rectal area or the skin of the perineum. Urination can become very painful and many women report symptoms that may seem more consistent with a urinary tract infection, such as frequent or painful urination.

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3. **Who gets vulvodynia?**

Very few studies have been done that give any information about the incidence of this disease or which women are most likely to get it.
Women of all ages, from adolescence through post-menopause, can develop vulvodynia. Although no one knows exactly how many women suffer from vulvodynia, the Vulvar Pain Foundation estimates that between 100,000 and 150,000 women in the US alone suffer from this condition. The Vulvar Pain Foundation also reports that they have identified cases in pre-pubescent children; however, this remains to be studied further.

Dr. Martha F. Goetch, of Good Samaritan Hospital in Portland, OR, attempted to find out what percentage of patients in a standard OB/GYN practice have vulvar pain and what the variation in normal vulvar sensation is. Dr. Goetch tested 210 patients over a six month period of time by questioning them for symptoms and then administering a “swab test”. 78 women (37%) showed some signs of vulvar tenderness and 31 (15%) fit the clinical definition for Vulvar Vestibulitis Syndrome. These women were then given a questionnaire to see if any common characteristics could be identified. A total of 50% had long-standing pain, most since their teenage years. Their symptoms did not suggest any cyclical pattern and, interestingly, 32% had a female relative who either had pain with intercourse or who found tampons painful. This raises the possibility that some genetic predisposition for VVS exists.

Dr. Stanley Marinoff, of the Center for Vulvovaginal Disorders in Washington, D.C., states in an interview in the NVA News that he has identified seven pairs of sisters and two mother-daughter pairs with vulvodynia, but that this needs more study. A study done in London, England indicated that most of the women affected by this were Caucasian, most likely to be in their thirties and middle-to-upper class. However, this is also the group of patients most likely to be well educated and to demand adequate treatment from their physicians. Another study at Wayne State University in Detroit suggests that vulvodynia patients are overwhelmingly white, which may be of significance since the Wayne State teaching hospitals and clinics are located in a very poor area of the city and their patient population is primarily African-American. Interestingly, this same study also found that most women with vulvodynia had never had children. More prevalence studies looking specifically at women of other races and income levels need to be done. It may prove that, like certain other disorders such as Chronic Fatigue Syndrome, vulvodynia is common in other ethnic and income groups who lack the resources to obtain proper diagnosis.

### 4. What causes vulvodynia?

That's the big question that researchers are trying to answer: right now, no one knows. It may have one or several different causes.

**Factors associated with pudendal neuralgia:**

Most cases of pudendal neuralgia probably originate from damage to the nerves innervating the genitals. It is well known that nerve degeneration causes ongoing pain: for example, many people with diabetes, atherosclerosis, herpes infection or HIV have damage to the nerves in the extremities that leads to constant tingling and pain (called "peripheral neuralgia"). The first two conditions damage the blood supply to the nerve, so that parts of the nerve die; herpes and HIV infection cause damage by direct attack of nerve tissue. In either case, it is the injured nerve that causes the pain. One researcher has reported a higher incidence of vulvodynia in women who are infected with HIV, suggesting that a process similar to HIV-induced peripheral neuralgia may be at work. (However, having vulvodynia does NOT mean that therefore you have HIV.)

Other cases of pudendal neuralgia appear to be due to nerves being "pinched" or compressed. A number of factors can contribute to compressed nerves, including narrowing of the opening in the spinal column from whence the nerve originates; obstetrical trauma; tumors or cysts of the spine, and perhaps ongoing muscular tension in the pelvis. However, neuralgia can originate at any level in the nervous system. Another neurologic pain disorder that resembles vulvodynia is phantom limb pain, which probably involves the brain as well as damage to the nerves of the amputated limb. Tumors in certain parts of the brain can also cause peripheral neuralgia. The most common involvement of the central (as opposed to peripheral) nervous system is probably dysregulation of the pain "filtering" centers high in the spinal cord and brainstem, leading a person to perceive normal sensations as painful.

Nerve compression probably does not contribute a lot to vestibulitis, which appears to be more of an inflammatory condition. It often has a different characteristic pattern of sensation than vulvodynia of neurologic origin. Women who have pudendal neuralgia usually complain of tingling, itching or
burning sensations. In fact, the classic presentation of a peripheral neuralgia anywhere in the body is as a spontaneous burning pain, which may be accompanied by shooting or lancing pains. These women do not usually experience more pain when urinating; women with VVS, on the other hand, can find urination to be extremely painful.

However, some women may have both vestibulitis and dysthetic vulvodynia. One theory about vulvodynia believes that an initial episode of inflammation, such as from an infection, can set up an abnormal pain feedback loop. Again, this may be due to dysregulation of pain control mechanisms high in the spinal cord and brain; it could also be the result of chronic pelvic muscular tension. In other words, the woman starts "guarding" or trying to protect herself from the pain by tensing the muscles; then when the inflammation is gone, the tension remains, leading to more pain.

**Factors associated with vestibulitis:**

Several authors distinguish between "acute" VVS and "chronic VVS". In the first case, it is often possible to find a precipitating cause such as infection, whereas in the women with chronic cases it is very difficult to determine what had caused it.

Whether there is an association between vestibulitis and HPV infection is one of the controversies about this condition. In one study, 13 women with symptoms of vestibulitis, who also developed white patches when the tender areas were washed with acetic acid and viewed under blue light, had biopsies of the affected areas. The tissue samples were then sent for DNA analysis to see if HPV was present. 11 of the 13 women showed signs of HPV. However, other studies suggest that HPV infection is actually rare in VVS. Some researchers have found that HPV infection is often completely without symptoms, and may even completely regress or vanish without treatment. One study found that HPV was present in half of the women who sought treatment for vestibulitis, yet that it had no relation to either the severity of symptoms or of the response to surgical treatment. A characteristic skin condition called "papillomatosis" is often found along with HPV: it looks like tiny ridges in the skin and often can only be seen with a microscope. This is often seen in women with vulvodynia; however, it can also be seen in people who have inflamed skin without HPV and even in some people who have no symptoms at all. It's important to remember that many women with vestibulitis show no signs of HPV, and the vast majority of women with genital warts will never go on to develop any vulvar pain syndromes.

Other physicians have suggested that VVS may be the result of infection with an unknown virus - in other words, one different from HPV. So far, no novel viruses have been identified in VVS.

Researchers at Carmel Medical Center in Haifa, Israel tried to determine if certain common viruses of the herpes family, known to be implicated in neurologic pain, were present in women with vestibulitis. They conducted polymerase chain reaction analysis to determine the presence of viral genes. They found virtually no prevalence of herpes simplex virus or cytomegalovirus among the subjects. However they DID detect HPV in 46 cases (54%). Only one woman of the 25 asymptomatic controls had HPV DNA in the vestibule. They concluded that vulvar vestibulitis is associated with human papilloma virus DNA in more than half of cases. However, Marinoff reports that some women do seem to develop vulvodynia in response to infection with herpes virus. He treats these women with acyclovir, an anti-viral drug, to minimize outbreaks.

An association with chronic candida infection has been found in a couple of studies. This is important because women who have VHS have often had many courses of treatment for vaginal yeast with imidazole family anti-fungals. These drugs have generic names that all end in "azole"; clotrimazole (marketed in the US as Gyne-Lotrimin vaginal cream); ketoconazole (Nizoral oral tablets); miconazole (marketed as Monistat vaginal cream), fluconazole (marketed as Diflucan oral tablets). It's not clear whether these drugs actually can cause vulvodynia or if they are just associated with it because VHS is often mistaken for a chronic yeast infection. However, women should take the package labeling for over the counter vaginal anti-fungal creams seriously; if your problem doesn't clear up after the time period allowed, it's time to see a doctor. Physicians should not try course after course of antifungals in their patients: if antifungals and antibiotics don't help after a few trials, referral to a specialist in vulvar pain disorders is probably indicated.

One study found that 17% of its subjects had a type of bacteria called ureaplasma in their Bartholin's glands. Another study found chronic inflammation of the Bartholin's glands in women with VVS of more than 5 years duration. The inflammation was identified by microscopic examination. These researchers found that 43% improved with laser treatment of the Bartholin's ducts and many of those who did not respond to laser did respond to surgical treatment. The Goetch study noted that several of the women studied had recently had a baby and that others were infected with Group B streptococcus.
Two studies have implicated early use of oral contraceptives and an early age of first sexual intercourse as risk factors and suggested that this could indicate the involvement of hormonal factors.\(^{(14)}\)

Another medication implicated in VVS is fluorouracil, an anti-cancer drug that is also being used to treat stubborn genital warts. The Goetch study noted that the worst cases were seen in women taking this drug.

Systemic corticosteroids, given for serious autoimmune diseases, and topical corticosteroids (often used to treat persistent vulvar itching) are also a possible cause of vulvar pain. These are also treatments for allergic reactions: however, one study suggests that allergy or localized immune reaction is NOT a common cause of vestibulitis.\(^{(33)}\) Topical corticosteroid creams in particular may cause thinning and sloughing off of the top layers of skin where they are applied. Both systemic and topical corticosteroids can also cause worsening of undiagnosed infections by counteracting the immune response that causes inflammation, but that also fights the infection as well. There are also anecdotal reports that some women develop VVS after taking Accutane. This needs to be further studied.

The Fibromyalgia Network mentions that vulvodynia is often found in women with Fibromyalgia Syndrome (FMS), which is a muscular pain disorder of uncertain etiology, and which is related to Chronic Fatigue Syndrome. Abnormally high levels of a neurotransmitter involved in regulating pain sensation, called Substance P, have been found in people with FMS and it's possible that at least some cases of VVS are due to abnormalities of the pain perception mechanisms in the body.\(^{(15)}\) It's interesting that genetic factors in VVS were suggested by Goetch,\(^{(7)}\) because FMS is believed by many researchers to also involve genetic predisposition.

There is also the possibility that abnormally high levels of urine oxalate may be involved. Drs. Clive Solomons, M.H. Melmed, and Susan Heitler of Rose Medical Center in Denver, Colorado have suggested that oxalate may be irritating the vulvar tissues during urination, and are currently conducting a study to see if neutralizing oxalates by taking oral doses of calcium citrate is of value to treat VVS.\(^{(16)}\)

A recent study suggests that, while oxalates may be an aggravating factor for some women with vulvodynia, it does not appear to be causative of the condition. Drs. Baggish, Szé and Johnson of the Department of OB-GYN at Good Samaritan Hospital in Cincinnati, Ohio conducted a controlled study comparing urinary oxalate levels in women with vulvodynia and asymptomatic healthy controls. 130 patients with vulvodynia and 23 control volunteers had their 24 hour urinary excretion of oxalate measured. In addition to measuring 24 hour volume and concentration, peak oxalate levels were measured by the hour. There was no difference between the vulvodynia and control groups in any of the measured oxalate parameters, although women with vulvodynia had significantly more frequent voidings. Of this group, 59 patients were treated with a low oxalate diet and calcium citrate for 3 months and then evaluated for response. The study found that 24% of the oxalate treatment group (14 women) had an objective improvement but only 10% (6 women) could have sexual intercourse without pain.\(^{(39)}\) The low treatment response rate is discouraging; however, some women may still benefit from the anti-oxalate treatment.

One study mentions alterations in vaginal pH as another common finding.\(^{(11)}\)

Finally, a number of immune changes have been found in vulvodynia, although their significance remains unclear. While a detailed discussion of immunology is outside the scope of this paper, the findings are presented below:

The Wayne State University researchers mentioned previously also found mast cells in the patient group. Mast cells are associated with inflammatory allergic reactions and are also found in interstitial cystitis.\(^{(42)}\)

In a study at Johns Hopkins in Baltimore, researchers looked for levels of two cytokines (immune stimulating chemicals) associated with inflammation: interleukin-1 beta and tumor necrosis factor-alpha. They found significantly higher levels of both these chemicals in women with VVS when compared to women without vulvar pain. One especially interesting aspect of their study is that the levels of these cytokines was *lowest* closest to the site of the greatest pain.\(^{(43)}\)

Pathologists at University Hospital Dijkzigt in Rotterdam, in the Netherlands, did a histopathologic study of biopsies from 12 patients with VVS and 12 age matched controls. They found a chronic inflammatory infiltrate in all of the patients with vestibulitis and none in the control group. This infiltrate was composed of T-lymphocytes, with small numbers of B cells, plasma cells, mast cells and occasional monocytes. An immune globulin important in antibody reactions, IgG, was found in plasma cells of 75% of the test group. This indicates chronic inflammation and possibly an autoimmune origin; however the researchers stated that an autoimmune etiology can neither be
confirmed nor rejected based on this study. They also observed some possibly pre-cancerous changes in the cells of two patients (mild dysplasia), which is interesting in light of the fact that neither the patient nor the control group showed any sign of carcinogenic HPV strains. To quote their abstract: "Minor vestibular glands were observed in 8 (66%) patients and were associated with a periglandular inflammatory infiltrate. Squamous metaplasia was observed in 4 (44%) patients. Epithelial hyperplasia was present in 10 (83%) patients with mild dysplasia in 2 (16%)." (44) This might be partly explained by another intriguing immunologic finding. Researchers at the University of Iowa found impaired natural killer lymphocyte activity in VVS when compared to healthy controls. Natural killer cells are a key part of the body's defense system against cancers. Normally, the activity of natural killer cells increases in response to high levels of interleukin-1 and interferon-alpha. (45)

Finally, researchers in Boston found some similarities between VVS and interstitial cystitis when cells obtained by biopsy were stained with a acid-Schiff/colloidal iron stain and with Van Gieson counterstain were compared to biopsies from healthy patients. In interstitial cystitis, cells stained with this process fluoresce. They found immunofluorescence in VVS and suggest that vascular injury associated with altered central neuronal processing could explain the positive immunofluorescence findings in both VVS and IC. (46)

5. How is Vulvodynia Diagnosed?

There is no specific test for vulvodynia per se. The diagnosis is based on medical history, looking for redness, swelling and/or pain, and ruling out other illnesses. There are a number of tests that should be done to both rule out other illnesses and to look for infection or another treatable cause of the symptoms.

Many cases are initially diagnosed when women who have pain with intercourse consult a doctor. Other cases are often detected only after many failed attempts, either by the woman herself or by her physician, to treat what appears to be a chronic vaginal bacterial or yeast infection. It's very important to seek a proper diagnosis from a physician or other qualified health provider such as a nurse practitioner or physician's assistant. This is because there are some very serious conditions that can cause similar symptoms.

**Among the conditions that must be distinguished from vestibulitis are:**

1. common vaginal infections caused by candida ("yeast"), trichomonads and bacteria;
2. genital herpes infection;
3. infection of the Bartholin's glands;
4. spasm of the vaginal muscles (vaginismus);
5. allergic or irritant reactions;
6. various fungal infections including candida and tinea;
7. certain immunologically caused skin diseases which can cause vulvar ulcers or inflammation including psoriasis and the "lichens": - lichen sclerosis, lichen planus and lichen simplex chronicus;
8. the immune-mediated vesiculobullous disease group, which includes vulvar pemphigus, benign familial pemphigus, pemphigoid, linear IgA disease, and dermatitis herpetiformis.
9. a number of systemic diseases including lupus, pellagra, Behcet's syndrome and Reiter's Disease;
10. pain due to genital warts or infection with the virus that causes them (human papillomavirus or HPV)
11. vulvar irritation due to medications such as corticosteroids;
12. interstitial cystitis or urethral syndrome
13. certain cancers that mimic vulvar dermatoses including extramammary Paget's disease, squamous cell carcinoma, and vulvar intraepithelial neoplasia.

**The examination**

First, a physician or other practitioner should do a careful visual inspection of the area, looking for obvious ulcerations, genital warts, herpes sores, inflammation of the Bartholin's glands (at the base
of the vaginal opening) or inflammation of the Skene's ducts on the external vulva. He or she should take vaginal slides and cultures to rule out common and uncommon vaginal infections. In addition to slides for trichomonas, bacteria and yeast, it is important to rule out sexually transmitted diseases such as chlamydia and gonorrhea. Any unusual secretion from the urethra, the Bartholin's glands or the Skene's glands should be cultured, and a pap smear should be taken if any genital warts are noted. It is also necessary to culture for unusual organisms such as ureaplasma or mycoplasma because these organisms often don't show up on a routine culture. In persons with urinary symptoms, urine and urethral cultures should be taken. Urethral cultures are particularly important: sometimes a urethral infection will not show up on a urine culture and can greatly contribute towards the woman's pain. One physician also recommends testing the vaginal pH, since too much acidity in the vaginal secretions may contribute to vulvar inflammation.

The practitioner should take a cotton-tipped swab and gently touch various areas of the vulva to see if the pain can be localized to one area. Often, women who have previously described the pain as around the inner vaginal lips will find that the pain is actually in the hymen itself when the swab is used.

This is often a good time to educate women about vulvar anatomy. Many women believe that the hymen disappears after first sexual intercourse. Actually, this is not true: the hymen remains but is torn. A woman can locate her hymen by taking a mirror and flashlight and inspecting the opening to the vagina. A woman who has had sexual intercourse before will probably notice several "petals", often described as flower-like, directly at the opening to the vagina. A woman or girl who has never experienced vaginal penetration will usually find a kind of membrane or ring around the entrance to the vagina that considerably narrows the vaginal opening.

The practitioner should wipe the vulva with a mild solution of acetic acid (read here: vinegar and water) and then view it under a blue light to see if any areas turn white. These may be areas which have been infected with the Human Papilloma Virus (HPV) - although this is disputed; one paper suggests that acetic acid does not provide a very good guideline as to HPV infections. It may be necessary to examine these areas with a culposcope (a special kind of microscope that lets the practitioner view the cells while still in place) to check for both signs of the virus and for cancer, since HPV is implicated in both cervical and vulvar cancers. Depending on what is seen, a biopsy may be needed. Biopsies in VVS often reveal inflammatory cells; however, at least one paper suggests that inflammatory cells can be seen in women who have no vulvar symptoms at all and thus may be a normal finding.

People researching the connection between vulvodynia and interstitial cystitis have recently developed an interesting test. One theory about painful urogenital syndromes is that the cell walls lining the mucosa of the area have become "leaky" and have altered permeability to potassium ions. One study compared the infusion of small amounts of saline solution with potassium chloride of the same concentration in patients with interstitial cystitis, benign prostatic hypertrophy (BPH), muscular contraction disorders (detrusor instability), acute urinary tract infection and healthy controls. These researchers infused about 40-50 mL of one solution into the bladder, removed it and then infused the same amount of the other solution and tried to see if the patient could tell the difference. To quote their results: "Neither normal subjects nor patients with interstitial cystitis reacted to water administered intravesically. There was marked sensitivity to intravesical potassium in 75% of patients with interstitial cystitis versus 4% of controls (p <0.01). Only 1 patient with BPH responded to potassium and none of the 5 with chronic urinary tract infection responded. All 4 patients (100%) with a current acute urinary tract infection reacted positively to the potassium challenge. Of 16 patients with detrusor instability 25% responded." Thus, this test may prove to be helpful in determining if a particular case of vulvodynia is inflammatory or neurologic. It may be of particular help to vulvodynia patients with urinary symptoms.

6. How is vulvodynia/vestibulitis treated?

Unfortunately, for most women with VVS, there are no magic cures. Sometimes an infection that will respond to medication is found, such as ureaplasma, candida, or strep. In a lucky few, it clears up on its own after 6 - 12 months. Some women develop vulvar pain as part of the hormonal changes of menopause. This particular problem often responds to estrogen creams or estrogen replacement therapy.

But for many women, the treatment is symptomatic, to try to reduce the pain. A prescription anesthetic, xylocaine (available both as a jelly and a liquid solution), may be helpful if applied
directly to the sore areas. Unfortunately, the effects last only for a couple of hours and repeated applications can cause damage to the underlying skin. Xylocaine can very useful for intercourse, however, and also during pelvic examinations and sometimes during tampon changes. Some physicians are injecting xylocaine directly into the affected area to create a nerve block. The effects of a nerve block can last from a few hours to a couple of days. Unfortunately, the more often you inject a nerve, the less responsive it becomes to the anesthetic.

Topical corticosteroids are often prescribed for vulvar itching, but seem to be of little help in VVS. If the vagina is too acidic, one doctor recommends baking soda douches. This appears to help a few women, is inexpensive and non-toxic.

Several studies have treated women who show also signs of HPV infection with interferon, (which strengthens the immune system), with some success. However, the relapse rate is apparently quite high, and at least one study suggests that interferon may work better on women who do *not* have signs of HPV infection. These researchers suggest that interferon may work, not by killing HPV, but by a general anti-inflammatory property.

Anticonvulsants are also prescribed for vulvodynia. Some physicians are experimenting with certain anticonvulsants known to work in other neurologic conditions involving shooting pains, such as trigeminal neuralgia (a pain disorder of the face), herpes related ("herpetic" neuralgia) and phantom limb pain. The most effective drugs for these conditions are carbamazepine (Tegretol), gabapentin (Neurotonin) and clonazepam (Klonopin). However, no controlled studies have been done of antidepressants for vulvar pain.

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Capsaicin is an extract of red pepper that destroys certain peripheral nerve fibers. It's commonly used for neurologic pain from diabetes, HIV infection, herpes infection and other disorders that damage nerve tissue. It is also used in the treatment of interstitial cystitis. The NVA News mentions an ongoing study of capsaicin by Dr. Hylina Zycznski of McGee Women's Hospital. Nine patients who applied capsaicin topically to the vulva for 6 weeks reported "significant relief". This study does not appear to have been published but it was presented at the first NIH Symposium on Vulvodynia. However, capsaicin also produces a significant burning sensation when applied to the skin. It may not be appropriate for patients with vulvodynia due to inflammation. (38)

Physical therapy may be of some help: not only do women often develop problems from the alterations of posture needed to avoid putting pressure on the vulva during walking and sitting, but it may be helpful by relaxing chronic tension in the pelvic muscles as well. (21) Many researchers believe that women develop chronic muscular tension in the vaginal area as a result of pain and that this can lead to a cycle of pain --> tension --> more pain. Dr. Howard Glazer, a psychologist in New York, claims that biofeedback and pelvic muscle exercises involving relaxation and muscle strengthening are helpful to some women with VVS. He proposes that vulvodynia may persist after an initial infection that has resolved. He believes that some women develop unconscious muscle tension in the pelvis and that this contributes to muscle spasm and pain perception. He has published a study of 28 patients. (37) Even though the study sample was small, his findings are in keeping with findings in other chronic pain syndromes. (22)

Opiate and other standard pain relief drugs do relieve vulvar pain in high doses, according to Dr. Marinoff. (36) The latest opinion of pain management specialists is that these drugs do not cause addiction when used for legitimate pain conditions under the supervision of a physician. Unfortunately, one effective treatment for neurologic pain cannot be used in vulvar pain: cutting the nerve causing the problem. The nerves that innervate the vulva also play a key role in bladder control. Cutting the pudendal nerve results in urinary incontinence. However, the vulvar vestibule CAN be removed without causing incontinence. There are two main surgical procedures, which can be done either with laser or by traditional means: perineoplasty and vestibuloplasty. In perineoplasty, the entire vulvar vestibule is removed, whereas in vestibuloplasty, the nerves that branch off the pudendal nerve directly to the vestibule are cut but most of the vestibular skin remains intact.

The most optimistic studies report that 60-85% of women respond to surgical excision of the affected area. (20,23) Other investigators have not found such encouraging results, and warn that approximately 10% of women may experience worsening of symptoms after surgery. (24) In one study, researchers found that of 11 women who underwent perineoplasty, 9 experienced improvement whereas none of 10 control patients experienced relief when only vestibuloplasty was performed. (35)

Laser treatments burn off the affected tissue. There are reports that carbon dioxide laser causes bad burns and can worsen vulvodynia. For this reason, some physicians feel very strongly that carbon dioxide laser should NEVER be used as a treatment. However, certain other laser treatments, such as dye laser are OK. One study of dye laser found that 43% of 163 patients improved. A recent study attempted to find out who were the women most likely to improve from surgery or laser. They found that women who had an acute onset, relatively mild pain and whose pain was clearly localized to one area were most likely to benefit. Women whose symptoms were of short duration (i.e. they had had vulvodynia less than 1 year) are also more likely to respond to surgical treatment. (38) However, even these women may not respond well and a few worsen. Women with generalized vulvar pain are poor candidates for surgery or laser.

Other researchers have concluded that women who have vulvar vestibulitis associated with pain with intercourse since their first episode of intercourse and in those with associated persistent vulvar pain will have a poor response to surgery. They suggest that "treatment approaches other than surgery should be considered for such patients". (28)

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7. Pregnancy and vulvar pain:
Pregnancy can impact on vulvar pain in several ways. First, there is the problem of getting pregnant. Then there is the impact of the pregnancy before birth on vulvar pain and vice versa. Next, there is the concern of pain relief during labor and delivery and finally, there is the impact of childbirth and vaginal delivery on the vulva in the postpartum period.
Before the Pregnancy:
Some of the medications women use to treat vulvar pain may cause birth defects. This is most true of the antidepressants. If at all possible, these should be discontinued before trying to become pregnant. However, it is very important that a physician be consulted before discontinuing any medications. Do NOT wean yourself off antidepressants without a doctor's supervision.

FDA Pregnancy Classifications:
The FDA classifies drugs into 5 categories of potential for harm to the fetus.\(^{(27)}\) These are:

- **A**: No risk demonstrated to the fetus in any trimester.
- **B**: No adverse effects in animals, no human studies available.
- **C**: Only given after risks to the fetus are considered: animal studies have shown adverse effects; no human studies available.
- **D**: Definite fetal risks, may be given in spite of risks in life-threatening situations.
- **X**: Absolute fetal contraindications, not to be used any time during pregnancy.

**Pregnancy Classification of drugs commonly used to treat VVS:**

Tricyclic Antidepressants:

- Amitriptyline (Elavil): C
- Nortriptyline: C
- Imipramine C

Anti-neuralgia agents:

- Gabapentin (Neurotonin): C
- Carbamazepine (Tegretol): C
- Clonazepam (Klonopin): C

Serotonin Reuptake Inhibitors

- Fluoxetine (Prozac): B*
- Paroxetine (Paxil): C*
- Sertraline (Zoloft): B*

* note: we don't know long term effects of SSRIs on the fetus because no human studies are available. Physicians recommend that women discontinue Prozac, Zoloft or Paxil prior to becoming pregnant.

(Ratings obtained from _Nursing 99 Drug Handbook_ and _Mosby's 1993 Nursing Drug Reference_.)

In addition, women taking calcium citrate and following the low oxalate diet need to make some changes. Marinoff states that doses of 1200-1500 mg. of calcium citrate per day are OK for most women, and do not cause harm to the fetus. However, higher doses can lead to kidney stones in the mother.\(^{(34)}\)

More problematic is the low oxalate diet. This diet is lacking in many necessary nutrients for both fetus and mother. The mother may need to consult a registered dietitian for help in planning her diet.

Becoming Pregnant:
Next: how do you get pregnant if intercourse is too painful to tolerate? It's best if the woman learns to detect when she is ovulating so that she can maximize her chances of becoming pregnant from
one act of intercourse. The most commonly used methods for this are taking basal body temperature and observing the vaginal secretions for changes in the cervical mucus indicative of ovulation.

Rather than launch into a detailed discussion of ovulation detection here, I refer people to the excellent FAQ put together by the alt.support.infertility newsgroup called "Low Tech Ways to Help You Conceive". This FAQ, along with another excellent FAQ on ovulation predictor kits, can be found at Fertile Thoughts.

Some doctors think it's all right to continue using small amounts of topical anesthetics such as xylocaine jelly while trying to get pregnant. If this doesn't work: well, intercourse is not the only way a woman can get pregnant. Some people have thought up very creative "sperm delivery systems". Turkey basters have been used for years by lesbians attempting to become pregnant and can be helpful. One doctor even boasts about his "turkey baster twins". Basically you can use either sperm from a sperm bank or sperm from your husband, male lover or friend, put it in the baster and inject it. Probably, the smaller the injector used, the more comfortable it will be. For this reason, some women may wish to use 5 or 10cc syringes, which should be available from your doctor or local women's health clinic.

During the pregnancy:
Does pregnancy worsen vulvodynia either during pregnancy or after delivery? There are no studies on this subject. In an issue of the NVA News, Dr. Marinoff states that about 1/3 of his patients improve, 1/3 get worse and 1/3 stay about the same. The growing fetus definitely places more pressure on the pudendal nerve and thus may worsen vulvodynia of the pudendal neuralgia sub-type. There is also more pressure on the bladder and urethra, which may aggravate urinary symptoms. However, there is an increase in circulating steroid hormones during pregnancy, including estrogen and cortisol. This may cause some cases of inflammatory vestibulitis to improve. (34)

Dr. Marinoff notes that some women have their first onset of vulvodynia during or after a pregnancy. In that case, he believes that the vulvodynia is most likely to recur with subsequent pregnancies. (34)

The Delivery and Post-partum Period:
There is no medical reason why a woman with vulvodynia must have a Caesarean section, even if she has had previous vulvar surgery. Each case is individual: if the vulva is heavily scarred, an episiotomy may or may not be needed to prevent tearing. There are women with vulvodynia who go through labor and delivery without any anesthesia at all; however, many women do elect to have at least an injection of local anesthetic directly to the vulva for examinations to determine cervical dilation and for the delivery. Other women prefer to have epidural anesthesia. This type of anesthesia can make labor and delivery much more comfortable and the woman usually retains the ability to walk and does not have the severe headache associated with a full "saddle block". However, it can lengthen the time needed to push the baby out and, in the hands of an overly cautious or inexperienced physician, leads to an increased rate of Caesarean sections. Thus, the decision to have an epidural block must remain with the patient herself.

After the delivery, some women elect to go directly back on medications they had discontinued during the pregnancy. These women should not breast feed because most medications contraindicated in pregnancy can also be excreted in breast milk. Other women stay off medication and try to determine if pregnancy has caused their condition to improve. In some cases improvement is permanent; in others the woman returns to her previous level of pain and function within about 6 months after the delivery. Unfortunately, there is no good way to predict who will improve with pregnancy and who will not or who will become worse.
that she knows more about the condition than her physician! It's difficult to find a physician experienced in treating vulvodynia and some still cling to outmoded ideas that the pain is psychosomatic in origin. Vulvodynia can be treated by gynecologists; I have also found gynecologic urologists and pain management specialists to be better informed than most other physicians.

I recommend that people contact the National Vulvodynia Association at (301) 299-0775 for a referral. It may also be helpful to seek out physicians who have actually published on this disorder. All footnotes in this article include the names of the physicians who wrote various articles and the research institutions that they are affiliated with. The reader may want to contact the gynecology departments of the listed research hospitals to try to get a referral in her own geographic area.

Dr. Howard Glazer also maintains a list on the Internet of professionals who treat VVS at http://www.vulvodynia.com/vvpros_frm.htm.

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9. **Coping strategies and self-help tips:**

**Support:**

Obviously, vulvodynia can interfere drastically with a woman's life. Proper information and support are very important in coping with VVS. The Vulvar Pain Foundation (listed under resources in section VII) both publishes a newsletter and maintains a list of local support groups. I strongly recommend that women with this condition get in touch with them. They are in contact with physicians who are knowledgeable about vulvar pain and may be able to put women with VVS in touch with physicians in their local area. They may also know of a VVS support group in your community.

Women with VVS may also want to consider psychological counseling by a therapist experienced in chronic illness. VVS, like all chronic pain disorders, can be extremely debilitating. This illness, like any painful illness, can interfere with many of the person's usual responsibilities; family members or friends may become angry about having to compensate for this. In addition, VVS carries the problem that it is a disorder that is very intimate and personal; very often, women are reluctant to speak about it. Because it involves the sexual organs, a woman may feel great shame about it. Her self-image can be drastically affected. She may feel that she is "less womanly" or no longer sexually attractive. This can be quite exhausting and very demoralizing.

**Sexual impact:**

Vulvodynia can cause a terrible strain on marriages or other sexual relationships because it makes many forms of sexual contact difficult or impossible. It is very important for the medical practitioner to validate the woman's experience. There are some tragic cases where relationships have broken up because a physician suggested that the pain was psychogenic and due to the woman "subconsciously rejecting" her husband or lover. Good communication between sexual partners is essential and relationship counseling may be helpful. While vaginal penetration is often out of the question, some people find other methods of sexual expression that can take its place. Xylocaine applied to the sore areas can sometimes make intercourse possible again. However, this doesn't work for every woman.

In an issue of the NVA newsletter, Dr. Gae Rodke recommends the use of a 4% liquid solution of xylocaine before intercourse, rather than jelly. This is because the jelly tends to transfer to the male partner, decreasing his sensation and often prolonging penetration which can be painful to the patient, even with the anesthetic. She advises women to place the solution on a cotton ball and place it right at the vaginal opening for a period of 5 to 10 minutes before intercourse. She also recommends using a lot of lubrication and, after intercourse, placing a cold compress on the area to reduce any reflex redness or swelling.\(^{(35)}\)

**Important note:** do NOT use oil or petroleum based lubricants such as Vaseline if you are also using latex condoms. They will eat right through the condom in a matter of minutes. Instead, either use a good water based lubricant such as For-play, or Astroglide (available at most places that sell sexual aids, or by mail order); or else use lambskin or polyurethane condoms. Also, many women with
Vulvodynia and Vulvar Vestibulitis Syndrome FAQ v2.3
Published on Physicians Practice (http://www.physicianspractice.com)

Vulvodynia are sensitive to spermicides: it’s necessary for these women to avoid not only contraceptive jellies and foams, but also certain lubricants that contain nonoxynol-9.

**Menstruation:**
Another little discussed factor is the impact vulvodynia can have on menstruation: what is a woman to do during her menstrual period if she finds inserting tampons and wearing menstrual pads to be very painful? Many women find that the tampon string is quite irritating but that they can tolerate the tampon if the string is either cut off prior to insertion, or pushed far up behind the pubic bone. Some women find that they can tolerate a brand of menstrual pad that has a cotton cover but cannot tolerate pads with the more “absorbent” synthetic surfaces. All cotton cloth menstrual pads are also available by mail order (details on how to obtain them are given in the resources section). Another alternative is to use a diaphragm or cervical cap to catch menstrual flow, although some women cannot tolerate the stretching of the vaginal opening necessary to insert them. Topical xylocaine may be helpful with insertion. The Vulvar Pain Foundation reports that rolls of absorbent cotton can provide a comfortable and highly absorbent alternative to menstrual pads. You cut the cotton into strips the size of regular pads, fold and place them in your underwear.

**Difficulty with urination and other pain relief measures:**
The most commonly reported helpful intervention is to keep the urine dilute by drinking lots of fluids.

A few women find that ointments such as A & D Ointment or Desitin are soothing. They can also be quite helpful, as can Vaseline, in protecting the inflamed tissue during urination.

Another way to help painful urination to pour a cup of water over the vulva while urinating: this dilutes the urine and helps to wash away any irritating residue.

It also helps to sit slightly forward when urinating, as this directs the stream straight down and it does not touch the skin.

Rinsing the vulva with plain water several times a day helps some women. A special bidet, that removes the need to wipe with toilet paper and which delivers both a rinse and an air dry, is available from Lubidet USA. Their phone number is in the resource section.

Carefully avoiding all potential irritants on your underwear, such as laundry soaps and bleaches, may help. Some women find that they can tolerate underwear washed with a mild, non-perfumed soap such as Castile Soap, and run twice through the rinse cycle. Others simply do without.

It may be possible to relieve pressure on the vulvar area when sitting by placing a notepad under yourself, in such a way that the edge elevates the pelvis. A type of pressure relief cushion called an Isch-Dish may be helpful. (Source is listed in the resources section.)

Many women who must wear pantyhose or stockings for work, wear brands with a cotton crotch over all-cotton underwear. They then slit the pantyhose crotch to relieve binding. Other women rely on old fashioned garter-belts and stockings. A product called Scantihose was designed to avoid bumps or ridges in clothing, and comes completely up the leg, unlike older stockings that can’t be worn with shorter skirts. Ordering information is in the resource section.

Many women find that perfumed soaps, or even completely plain soaps, aggravate the irritation. This may also be true of colored or scented toilet paper as well. Some women find tub bathing to be possible if they avoid all bath oils or perfumes; others find that any tub bathing worsens the situation and only take showers. A hand held shower massager is preferable to an overhead nozzle; it makes it much easier to wash away any soap residue that may remain after washing. Natural glycerin soap may be helpful, as it has no residual drying effects. One woman I know discovered that using distilled water to wash the vulvar area rather than tap water relieved some of the irritation. She speculated that perhaps the chlorine in the tap water contributed to her condition. One gynecologist advises his patients to keep the vulva very dry: he tells women to first wash with distilled water and pat the area dry; to then use a hand held blow dryer (on cool please!) to further dry the skin and to then apply cornstarch.
The Vulvar Pain Foundation mentions that some women find applying warm soaked tea bags to the vulva to be soothing. Some women put the tea bags on menstrual pads to hold them in place. Others take sitz baths in which tea bags have been soaked. Many women report cold compresses to be helpful.

10. **List of Foods High in Oxalates**

Solomon and Melmed recommend complete avoidance of all foods high in oxalate. These include:

- Beer, berry juices like raspberry juice, tea, cocoa, Ovaltine, beverage mixes, baked beans in tomato sauce, peanuts and peanut butter, pecans, soybean curd (tofu), all berries, concord grapes, citrus peel, rhubarb, tangerines, chocolate, vegetable and tomato soups, fruit cake, grits, wheat germ, black pepper (beyond a teaspoon a day), beans of all kinds, beets, celery, chard, collards, dandelion greens, eggplant, escarole, kale, leeks, mustard greens, okra, parsley, green peppers, sweet potatoes, rutabagas, spinach, summer squash and watercress.

They recommend that foods with a moderate amount of oxalate should be eaten in moderate amounts, no more than two half-cup servings a day. These include:

- Coffee, cranberry, grape, orange and tomato juices, sardines, apples, apricots, black currants, sour cherries, oranges, peaches, pears, pineapple, plums, Italian prunes, chicken noodle soup (dehydrated), cornbread, sponge cake, canned spaghetti in tomato sauce, asparagus, broccoli, carrots, corn, cucumber, green peas, iceberg lettuce, lima beans, parsnips, tomatoes and turnips.

In addition, they recommend that women with VVS take no more than 250 mg of Vitamin C a day, because it is a chemical precursor of calcium oxalate. They also state that there is some evidence that drinking small amounts of milk or eating dairy products *with meals* (emphasis in the original) helps in reducing the amount of calcium oxalate to the body.

11. **Books that may be helpful:**

Alas, there are no books written on this illness. However, women with vulvodynia may find the following books of interest:

**The Low Oxalate Diet Book**
General Clinical Research Center (H-203)  
The University of California  
San Diego Medical Center  
University Hospital  
225 Dickenson Street  
San Diego, CA 92103  
USA  
Cost: $5 each plus postage and handling. Make checks payable to the Regents of the University of California

**Overcoming Bladder Disorders** by Rebecca Chalker and Kristine E. Whitmore, M.D. HarperPerennial Press, 1990  
ISBN # 0-06-092083-1 Cost: $9.95 US  
Contains good information about interstitial cystitis and urethral syndrome.

ISBN # 0-7890-0126-8 Cost: $24.95 (softcover)

**Our Bodies, Ourselves**; by the Boston Women's Health Book

Good general information on women's health care.


Best illustrations of female reproductive anatomy *ever*.

Can be ordered through:
Feminist Health Press
8240 Santa Monica Blvd
West Hollywood, CA 90046
(213) 650-1508
Cost: $19.95 plus tax and S&H. Call for shipping information.


Because there is not yet a reliable cure for vulvar vestibulitis, many vulvodynia sufferers are exploring herbal or other alternative medical treatments. This book is based completely on scientifically validated studies and discusses contraindications and adverse effects of herbs at length.


12. Organizations and resources for women with vulvar pain.

The National Vulvodynia Association
P.O. Box 4491
Silver Springs, MD 20914-4491
USA
(301) 299-0775
FAX: (301) 299-3999
Main NVA Webpage
Membership: $40 per year. Quarterly newsletter. Well worth the money: their newsletter is excellent. Back issues of the newsletter are available at $5 each.

The Vulvar Pain Foundation
Post Office Drawer 177
Graham, North Carolina 27253
USA
(910) 226-0704
Membership is $40 per year, which includes a quarterly newsletter. For $5 more, you can obtain copies of all back issues.

The Fibromyalgia Network
P.O.Box 31750
Tucson, AZ 85751-1750
USA
(805) 631-1950

Fibromyalgia Newsletter
Membership is $19 for US residents, $21 for Canadians for all others, includes bi-monthly newsletter.

The National Chronic Pain Outreach Association
7979 Old Georgetown Road, Suite 100
Bethesda, MD 20814-2429
USA
(301) 652-4948
Publishes a quarterly magazine, provides information about pain management specialists, sponsors conferences and publishes many resource materials, discounted to members.
Membership starts at $25

Interstitial Cystitis Association
110 N. Washington,
#340 Rockville MD 20850 1 800 HELP ICA
www.ichelp.org
The following document is available from these folks:
Transcript of the workshop on Vulvodynia and IC, from the 7th National Conference on Interstitial Cystitis
Also provide valuable information for those women whose vulvar pain seems related to inflammation of the urinary tract.

Embracing Concepts (makers of the Isch-Dish cushion)
40 Humboldt Street
Rochester, NY 14609
USA
(800) 962-5542

Ragtime (makers of all cotton cloth menstrual pads)
P.O. Box 9683
Berkeley, CA 94709
USA
(510) 843-3127

Glad Rags (makers of all cotton cloth menstrual pads)
Post Office Box 12751
Portland, OR 97212
USA
(503) 238-8624
(503) 282-0436

Life Cycles (makes a special bicycle seat that relieves vulvar pressure when cycling)
(303) 963-1149

Lubidet USA, Inc. (makes a special add on bidet that delivers warm water wash and air dry every time you use the toilet. Reported to be quite helpful although somewhat expensive)
(800) 582-4338
(303) 757-3031

L & L Hosiery (makers of Scantihose)
1-800-401-LACE (*note: Vulvar Pain Foundation members get a special discount.)
13. Internet Resources on Vulvodynia
Dr. Howard Glazer's Vulvodynia Web Pages
These are the most helpful vulvodynia resources on the Internet that I've found to date. In addition to the resources below, Dr. Glazer's page has a real time chat room and an extensive bibliography of vulvodynia articles.

Dr. Glazer's Main Web Page

Vulvodynia Professional Registry
a list of physicians who treat vulvodynia:

The Vulvodynia Mailing List
Join this mailing list to talk to many other women with vulvodynia.

Other Important Vulvodynia Resources
National Vulvodynia Association
Vulvodynia Page of the Center for Vulvar Diseases at U of Michigan

Non-vulvodynia resources that may be useful to persons with VVS

Fibromyalgia Newsletter

Interstitial Cystitis Association

Incontinence on the Internet

American Physical Therapy Association

International Foundation for Functional GI Disorders

National Association for Continence

Wound, Ostomy & Continence Nurse Society

Articles about the Treatment of Chronic Pelvic Pain (index)

HerpeSite- Herpes Online Personal Empowerment and Support

Post-Herpetic Neuralgia

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