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VULVAR PAIN (VULVODYNIA)

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What is pain?

Pain is a signal in the body that some disturbance has occurred. Chronic pain is persistent pain and it can continue after the cause has been cleared up. Some people suffer pain in the absence of any obvious injury or disease.

What is the vulva?

The vulva is the external, lower female genital organ and is covered by the hair between your thighs. It has outer lips (labia majora) and inner lips (labia minora) which extend from an area over the clitoris to below the vagina. The vestibule is the area between the inner lips that surrounds the vaginal opening. You can learn more about this area in 'The normal vulva' leaflet found on this website.

What is vulvar pain?

Vulvar pain is pain in any part of the vulva. It can be generalized everywhere or just in one place. It can vary in location from one time to the next. It can be mild or strong, occasional or constant. It can make sexual intercourse difficult or impossible. Tampons may be too painful to use. Tight clothing may be uncomfortable to wear. Simply wiping or touching the area can cause pain.

What causes vulvar pain?

Pain may be a symptom experienced as part of many different conditions such as infections, inflammatory skin disorders or possibly a growth. If you can see or feel anything abnormal on the vulva, see your health care provider.

The vulva is one of the most sensitive parts of the body. If it is traumatized by infection, sex without arousal or many treatments and other chemicals, it will feel painful or abnormally sensitive, even after the cause has been removed. Some abnormalities of the nervous system (known as dysaesthesia) can cause pain to be felt in the area without any of the above, but that is rare.

No one really knows for sure what causes the pain; doctors suspect that inflammation or injury to nerve endings that supply the vulva may be involved.

What if there is nothing abnormal to see?

There are some vulvar pain problems where all the conditions listed above have been excluded. It is these types of pain problem that are discussed in this leaflet. There is no evidence of any skin condition, skin swabs and biopsy findings are normal and there are no open areas or sores. Your health care provider may tell you “there is nothing **abnormal** to see”, that “there is nothing wrong”, or that “there is nothing to treat”. There are, however, two vulvar pain disorders that can be diagnosed. The names of these have changed as we have learned more about these conditions. The current names for these two major vulvar pain conditions are **localized vulvodynia** and **generalized vulvodynia**. You may have heard these called vestibulitis and vulvodynia in the past.

Some patients who have localized or generalized vulvodynia also have interstitial cystitis (a painful bladder condition) or irritable bowel syndrome (a chronic bowel disorder) as well.

What is localized vulvodynia?

Localized vulvodynia is pain that is caused by something touching a localized area of the vulva. This is most commonly the vestibule and so it may be called vestibulodynia. However, any other localized area of the vulva can be affected eg. the clitoris.

Women with **localized** vulvodynia have painful intercourse, or no sex at all, because of the pain at the opening of the vagina. Inserting tampons is painful. Women may not be able to ride a bicycle or wear tight jeans because of the pain. Just touching themselves may hurt. If they are not touched, they may not have pain.

What is generalized vulvodynia?

Generalized vulvodynia is pain and burning on or around the vulva (large and small lips as well as, at times, the vestibule). The area hurts most of the time, even when nothing is touching it.

Women with **generalized** vulvodynia describe burning, stinging, rawness and aching in the vulva. This can be a mild discomfort or more severe pain that can prevent daily activities. Sitting may be uncomfortable. There may be good days and bad days. Some women report an increased discharge with the pain. Urination may cause pain and burning. Prolonged sitting may hurt. At times, they may not be able to have sex, but, other times, they may have little or no pain at all.

What is there to see?

NOTHING! The vulva and vagina look normal.

How is vulvodynia diagnosed?

An accurate diagnosis is vital so that treatment is appropriate. Doctors may have difficulty making a diagnosis because more than one disease process may be present and tests may sometimes be needed to exclude infection etc. It is important to find a health care provider who understands the problem of vulvar pain.

It is very important to see a doctor. You may also be sent to a specialist who works in the area of vulvar diseases. The doctor will take your history. It is important that you tell the doctor about any creams or lotions you have used on the vulva and what products, if any, you use to wash the area. You will need to tell the doctor if sex has been a problem at any time. Stresses in your life may be relevant as well. The doctor will examine you thoroughly.

Localized vulvodynia is diagnosed by touching the area around the vaginal opening (vestibule) with a Q-Tip. Even light pressure can cause pain. A diagnosis of **generalized vulvodynia** is made when there is a history of generalized vulvar pain without any visible cause.

How is vulvodynia treated?

Successful treatment comes from the combination approach. Many women say they feel better knowing there is a name for their pain problem. Treatment approaches vary depending on your needs, but there are some standard suggestions. It is important to follow any treatment plan carefully.

A topical anesthetic ointment may help the pain. Some doctors ask women to apply an anesthetic ointment several times a day as a pain treatment. Topical anesthetic ointments are not only used to control pain but also to heal nerve endings. Use only those prescribed by your doctor as some of the anesthetic creams that can be bought over the counter contain a local anesthetic that can cause allergy if applied for a long time.

You may be prescribed medication used for depression or epilepsy. They will not be prescribed for depression but for reducing the pain and are part of the standard treatment regimen for chronic pain. Your symptoms are not considered to be imagined so don't be concerned if such medication is prescribed for you.

Physical therapy is often used to help these pain conditions. Vulvar pain can be associated with spasm and pain in the pelvic muscles and physical therapy can be helpful in teaching you to relax these muscles.

The correct diagnosis is very important. Do not self diagnose. It will be a great relief to have a solid diagnosis. Then carefully follow the treatment plan suggested by your health care provider. Talking to someone who understands the problems helps. You may want to seek counselling for your own issues or relationship problems that develop when sex is painful. Relaxation and stress management may also help you.

Acupuncture, massage therapy, meditation, cognitive behavioral therapy all have contributions to helping pain.

What can I do to help myself?

Do not treat your self with anything! Stop all previous treatments, especially anything bought 'over the counter'. Use only what is prescribed by your doctor. If itching is present do not scratch or rub the vulva. Do not excessively wash the vulva. Poor hygiene is not the problem but washing can make it worse. Do not use genital deodorants.

If the doctor prescribes medicine, use only what is necessary and only put it on the affected part. Excessive treatment with creams and lotions may cause contact dermatitis and this will make the discomfort last longer. Just like your eye, vulvar skin cannot cope with many chemicals. If you have any problem with your treatments, contact your doctor. Occasionally, in some people, treatment can cause an allergy and will need to be changed.

Wear loose, cotton clothes, avoiding tight garments and synthetic fabrics. Cold packs are soothing. Do not use sanitary napkins unless it is necessary.

Avoid uncomfortable sexual intercourse until you are ready to try it again. Talk to your partner about your problems and try other kinds of love making such as touching. Be open with your partner about the sexual things you like or don't like. When you are ready to try to have sex, ensure that you are excited enough so that discomfort will not occur. If you are aroused, natural lubrication will occur. If not, penetration should be avoided or the situation will self-perpetuate. Your doctor may suggest lubricants that may be useful. It may be helpful for you and your partner to get advice in this area. If you have on-going stresses get help with these also.

What if my physician can find nothing and tells me everything is completely normal and I am still having pain?

There are people who can help you. Continue to seek advice. Read all that you can. Call a teaching hospital or go on the Internet to find a health care provider close to you who deals with vulvar pain problems. Be cautious about 'alternative' medicines as these will not have undergone rigorous scientific testing. It is better to go to your doctor for advice.

There are good books and websites about these conditions.

Books about Vulvodynia

Glazer H, Rodke G. The Vulvodynia Survivor's Guide, New York, New Harbinger, 2002.

Stewart EG, Spencer P. The V Book. New York, Bantam, 2002.

Websites about Vulvodynia and Related Pain Problems

Endometriosis Association

8585 N. 76th Place
Milwaukee, WI 53223
Phone: 800-992-3636
FAX: 1-414-355-6065
endo@endometriosisassn.org
www.EndometriosisAssn.org

Interstitial Cystitis Association
110 North Washington Street, Suite 340
Rockville, MD 20850
Phone: 301-610-5300 (800-HELP-ICA)
FAX: 301-610-5308
icamail@icahelp.org
www.ichelp.org

National Vulvodynia Association
P.O. Box 4491
Silver Spring, MD 20914-4491
Phone: 301-299-0775 FAX: 301-299-3999
Information: 703-777-3074
www.nva.org

Vulvar Pain Foundation
203 1/2 North Main Street, Suite 203
Graham, North Carolina 27253
Phone: (336) 226-0704
FAX: (336) 226-8518
www.vulvarpainfoundation.org

British Vulval Pain Society
www.vulvalpainsociety.org

