



VESTIBULODYNIA

(Also known as provoked localised vulvodynia, and previously known as vestibulitis)

This leaflet has been written to help you understand more about vestibulodynia - what it is, what causes it, what can be done about it, and where you can find out more about it. Another leaflet on the 'Information and leaflets' section of the British Association of Dermatologists' website deals with the related condition known as 'Vulvodynia'.

What is vestibulodynia?

The rather awkward name for this condition can be explained as follows:

- The *vulva* is the genital area in women. It consists of the pubic mound, the outer hair-bearing lips and the inner lips.
- The area inside the inner lips, where the openings to the vagina and the urethra (the tube from the bladder) are found, is called the *vestibule*. It is not lined with skin but with mucosa (like the inside of the mouth).

- Adding ‘*-odynia*’ to the end of a word such as vestibule or vulva (thereby creating the words vestibulodynia and vulvodynia) means that the condition affecting that area is a painful one.
- In vestibulodynia, pain is felt when any pressure, be it a touch or friction, is applied to the vestibular area. It is not uncommon.

What causes vestibulodynia?

Vestibulodynia has no single cause. Some people may have a tendency to develop it, as it occurs more often in those who have other problems with pain and its perception. Their nervous systems may work in a different way: the superficial nerve endings in the vestibule seem to become over-sensitive, and to react abnormally to touch, sending painful messages to the brain.

Half of the patients with vestibulodynia develop it after a “trigger event”, which may be something like an attack of thrush, having a baby, being unwell, or a stressful event such as moving house. In the other half, the symptoms come on slowly, with no obvious trigger.

Is vestibulodynia hereditary?

Not directly, although there may be a familial tendency.

What are the symptoms of vestibulodynia?

Pain occurs when the inner vulva or vestibule is touched. This often causes difficulties in having sexual intercourse, in using tampons and in the wearing of tight clothing.

What does vestibulodynia look like?

The skin of the vulva looks normal. This is important as other skin conditions, such as infections, cause the vulva to look abnormal as well as to feel sore. These conditions must be looked for and treated if found.

How will vestibulodynia be diagnosed?

Your doctor will make the diagnosis by listening to your story and then examining you to exclude other causes of pain in the area. Certain tests (such as taking swabs or even a biopsy - a tiny bit of skin to check under the

microscope) may occasionally be needed. Your doctor may apply pressure with a cotton bud to find the tender areas.

Can vestibulodynia be cured?

There is no simple cure, but most patients will respond to one or more of a variety of treatments, to the point at which it is no longer a problem.

How can vestibulodynia be treated?

Various treatments can be tried. Some of them may suit some women better than others; and so it is worth trying different things to see which will help you personally.

The following are sensible lines of treatment:

1. Avoid soap, bubble baths, shower gels, shampoos, special wipes and deodorants in this area. Wash with a soap substitute, as this will keep your skin soft and provide a barrier against irritation. Aqueous cream and emulsifying ointment are good soap substitutes, and can be bought over the counter. Use vaseline to protect the area from chlorine when you are swimming.

2. A local anaesthetic ointment can be used to numb the area, reducing discomfort, and “re-educating” the over-sensitive nerve endings. 5% Lidocaine ointment can be bought over the counter from your chemist. It may sting a little when first applied, but this will settle. Those with mild symptoms can use it as and when it is required. Those with more severe symptoms can apply it regularly. The ointment may also be applied 10 minutes before intercourse but, if a condom is being used, the ointment must be wiped off fully as it can interfere with its protective ability.

3. If your skin reacts to being scratched by showing red lines (a condition known as dermatographism) then an antihistamine taken regularly may help.

4. If none of these measures gives you enough relief, then oral medication may be needed to damp down pain appreciation by the central nervous system. Three types are commonly used:

a. *Amitriptyline*. This was developed as an anti-depressant but is now used for many pain problems (e.g. for migraine and post-shingles neuralgia). The dose should start at 10mg at night, and gradually increase each week by an extra 10mg per night. The effective dose varies from patient to patient but is usually between 20 and 100mg. Once the effective dose has been reached, you should stay on it for 3 months before gradually reducing it.

b. *Gabapentin*. This is an anti-epileptic drug, which is also used for pain. The dose should start at 300mg at night and gradually increase to 300mg three times a day. If necessary it can be increased to 600mg, 3 times daily.

c. *Pregabalin*. This is similar to Gabapentin but is used at the dose of 75-300mg, taken twice daily.

5. There is no scientific evidence that anti-candidal or low oxalate diets work for vestibulodynia.

What can I do?

Do not worry, as this condition is not dangerous or contagious. Follow the guidelines given above, and find what works best for you. Look at the stresses in your life (e.g. from your job, family, money, or partner) and try to reduce them as far as possible. High levels of stress will increase pain. Painful intercourse may have emotional and psychological effects on your relationships. It is important to understand this, and to communicate fully with your partner, discovering techniques that are comfortable and suit you both. Occasionally psychosexual counselling from an expert may help.

Where can I find out more about vestibulodynia?

There are many websites for vulvodynia and vestibulodynia but the

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information there is not always reliable.

In the UK: Vulval Pain Society

PO Box 7804

Nottingham

NG3 5ZQ

Website: <http://www.vulvalpainsociety.org/>

British Society for the Study of Vulval Disease

Website: <http://www.bssvd.org/>

In the USA: International Society for the Study of Vulvovaginal Disease

Website: www.issvd.org/

National Vulvodynia Association

Website: <http://www.nva.org/>

(Whilst every effort has been made to ensure that the information given in this leaflet is accurate, not every treatment will be suitable or effective for every person. Your own doctor will be able to advise in greater detail.)

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