PATIENT INFORMATION LEAFLET

VULVODYNIA AND VESTIBULODYNIA

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about vulvodynia. It tells you what it is, what causes it, what can be done about it, and where you can find out more about it.

WHAT IS VULVODYNIA AND VESTIBULODYNIA?

Vulvodynia means ongoing pain in the vulva (the female genital area from the clitoris to the perineum including the labia) when there is nothing abnormal to see and no known cause for the pain; and other diagnoses have been ruled out by examination and investigation.

Vestibulodynia is a term used for pain specifically arising at the entrance of the vagina, in the area known as the vestibule (the area of the openings to the vagina and the urethra), when any pressure, be it touch or friction, is applied. It is also called localised vulvodynia.

Vulvodynia can be generalised (involving skin around the inner thighs and buttocks) or localised just to the entrance into the vagina. Whether generalised or localised vulvodynia may be described as provoked (caused by touch) or spontaneous (occurring without touch as a trigger).

Many conditions affecting the vulva can be painful (e.g. infections such as thrush or genital herpes, as well as skin conditions such as eczema).

WHAT CAUSES VULVODYNIA?

The precise cause is unknown. The nerve endings in the skin of the vulva appear to become hypersensitive and account for the pain felt. Vulvodynia is one type of 'complex regional pain syndrome,' others including migraine and fibromyalgia. Stress is known to worsen the condition.

Vulvodynia is thought to affect about 15 in 100 women. It is not contagious or related to hygiene or hygiene products.

It may be primary (with no known cause) or secondary (following another condition)., Secondary vulvodynia may follow inflammation in the vulva, such as that caused by thrush or the overuse of topical and vaginal anti-thrush treatments).

IS VULVODYNIA HEREDITARY?

No.

WHAT DOES VULVODYNIA FEEL AND LOOK LIKE?

Pain occurs in the vulva, and occasionally involves the buttocks or even the inner thighs. It is often felt as a burning, stinging or raw sandpaper-like discomfort. These sensations may fluctuate in intensity and can be constant or intermittent. Symptoms may occur only in a small area or involve the entire vulva. The pain can occur spontaneously or when the vulva is touched.

Vulvodynia can lead to painful sexual intercourse, decreased libido, and communication barriers (for example, being embarrassed to talk about it). The ongoing pain can cause significant distress, anxiety and affect sexual relationships.

The skin of the vulva looks normal. This is important as other skin problems, such as dermatitis or infections, can cause the vulva to look inflamed, swollen, ulcerated

or with broken skin, very red, and to feel sore.

HOW WILL VULVODYNIA BE DIAGNOSED?

Your doctor will make the diagnosis by listening to your description of the problem and then examining you to exclude other causes of pain in the area. Taking swabs to look for infection or a biopsy (removal of a small sample of skin under a local anaesthetic to examine under the microscope) may occasionally be needed to rule out other causes, but there is no specific test to make the diagnosis.

CAN VULVODYNIA BE CURED?

There is no simple cure, but the condition can improve by one or more of a variety of treatments, so that it may no longer a problem.

HOW CAN VULVODYNIA BE PREVENTED AND TREATED?

Vulvodynia can be managed with appropriate self-care practices (discussed in the next section). If these do not help, then prescribed off-licence oral medication may be needed.

What is an unlicensed drug?

An unlicensed drug is one that has not been awarded a Market Authorisation by the UK Medicines Healthcare Products Regulatory Agency (MHRA) for specific condition(s). Drug licences are awarded following a rigorous process of evaluation by the MHRA, following an application by a pharmaceutical company. Once awarded, the licensed drug can then be marketed and sold in the UK.

In the absence of a licence, the drug may still be prescribed in the UK, provided there is funding available locally to pay for it. Additionally, there must be a clear body of evidence to confirm that the drug is effective for the condition in question and that safety concerns have been adequately addressed. Even after such evidence has been supplied it is still a matter for the local formulary group (a multidisciplinary group who make decisions on the prescribing of medicinal drugs at a local level) to make a final decision on a case-by-case basis.

What is the off-licence use of a drug?

The off-licence use of a drug is when a doctor prescribes it for a condition that is different from the licence awarded by the MHRA.

Three types of off-licence medicines are commonly used to treat vulvodynia:

1. *Amitriptyline or Nortriptyline*. These medicines were developed as anti-depressants but are now used for various pain problems (for example, for migraine and post-shingles neuralgia).
2. *Gabapentin*. This is an anti-epileptic drug, which is also used for pain.
3. *Pregabalin.* Similar to gabapentin, this medicine is used to treat epilepsy, but it can be used to treat pain.

    - *Intralesional injections.* Intralesional (into the vulva or the vestibule) injections (of steroid or local anaesthetic) may be considered if vulvodynia is triggered by touch.
    - Nerve blocks or botulinum toxin injections may help in very specific cases.
    - A local anaesthetic ointment can be used to numb the area, reducing discomfort. Lidocaine 5% ointment can be bought without a prescription. This, however, should be purchased on a doctor's advice. Lidocaine may sting a little when first applied, but this will settle. Those with mild symptoms can use it as and when it is required, however,

those with more severe symptoms may apply it more regularly. The ointment may also be applied 10 minutes before intercourse but must be wiped off fully if a latex condom is being used as it can interfere with its protective ability. Occasionally, long-term use of this ointment can cause irritation, but this is rare. The irritation will stop when lidocaine is discontinued.

SELF-CARE (WHAT CAN I DO?)

This condition is not life threatening or contagious. Follow the guidelines given below and find what works best for you. Look at the factors that increase stress in your life (e.g. your job, family, money, or partner) and try to reduce them as far as possible. High levels of stress will increase pain.

- Avoid prolonged sitting and wearing tight clothing in the genital area.
- 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. Greasy ointments are a good soap substitute and can be bought over the counter from chemists and at supermarkets without a prescription.
- Use petroleum jelly to protect the area from chlorine when you are swimming.
- If intercourse is painful this may have emotional and psychological effects on sexual relationships. It is important to understand this, and to communicate fully with your partner, discovering techniques and lubricants that are comfortable and suit you both. Psychosexual counselling from an expert may help.
- Referral by your healthcare professional to a 'Pain management clinic' or a dedicated vulval dermatology clinic may also be helpful. Speak to your healthcare professional about available options.
- Pelvic floor exercise. The pelvic floor is a group of muscles which are in the shape of a sling between the legs. These muscles keep the pelvic organs (bladder, uterus, and rectum) in place. If vulvodynia occurs with sex-related pain, this might mean that the pelvic floor muscles do not work as they should. Physiotherapy for the pelvic floor muscles can be helpful. Speak to your healthcare professional for more information.

These recommendations may suit some women better than others, so it is worth trying different things to see which will help you as an individual. Most women find that a combined approach including several techniques is the most effective way of managing vulvodynia. It is very common for the condition to have periods of flaring up as well as dying down. Overall, it will improve spontaneously in around 50% of women.

WHERE CAN I GET MORE INFORMATION?

Patient support groups providing information:

Vulval Pain Society
Web: https://vulvalpainsociety.org.uk/

British Society for the Study of Vulval Disease
Web: www.bssvd.org/

International Society for the Study of Vulvovaginal Disease
Web: www.issvd.org

National Vulvodynia Association (in USA)
Web: www.nva.org/

Web links to other relevant sources

BAD PIL for vulval skincare:
www.bad.org.uk/pils/vulval-skincare/

DermNetNZ:
dermnetnz.org/site-age-specific/vulvodynia.html
dermnetnz.org/topics/vestibulodynia/

Jargon Buster:
www.skinhealthinfo.org.uk/support-resources/jargon-buster/

Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links.

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

BRITISH ASSOCIATION OF DERMATOLOGISTS

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