#### **Associated vulval conditions**

#### Lichen sclerosus, lichen planus, eczema, psoriasis

There are also a number of skin conditions that can affect the vulva – a few are listed above. They are usually characterised by itchiness; the skin may be red and inflamed, as in eczema, or white patches may be visible, as in lichen sclerosus. Initial treatment is usually with a steroid cream or ointment. Diagnosis needs to be made by a doctor.

#### Painful bladder syndrome (PBS)

PBS (formerly known as interstitial cystitis) refers to chronic symptoms of urinary urgency and frequency, pain and burning, in the absence of a bladder infection.

Some people with vulvodynia also experience bladder symptoms, and it is possible to present with more than one vulval condition simultaneously.

## What unprovoked vulvodynia and vestibulodynia are NOT

**They are not sexually transmitted infections** and cannot be passed on to a partner. PBS and the skin conditions listed above are also non-infectious.

**They are not forms of vaginismus** (involuntary tightening of the vaginal muscles), though vaginismus can develop as a response to pain in the vagina or vulva.

They are real physical conditions and do not have a psychological cause. Psychological distress may develop as a consequence of ongoing pain or discomfort and in this instance patients (and their partners) may benefit from seeing a psychosexual counsellor.

### The Vulval Pain Society

The Vulval Pain Society is a UK registered charity, number 1118118, providing support and information to vulvodynia sufferers and their partners. It was set up in 1996 by gynaecologist Dr David Nunns and nurse Diane Hamdy.

#### **Contacts**

#### The Vulval Pain Society (VPS)

w: vulvalpainsociety.org.uk
e: info@vulvalpainsociety.org.uk
Post: VPS, PO Box 7804, Nottingham, NG3 5ZQ.

#### **UK Lichen Planus (UKLP)**

www.uklp.org.uk

#### **Further information**

Details of local support groups, workshops and treatment options can be found on the VPS website at  $\,$ 

#### vulvalpainsociety.org.uk

For further copies of this leaflet free of charge, please email or write to the VPS at the address given above, or you can download a copy from the Guides, leaflets and resources section of the VPS website. You may freely photocopy or copy the leaflet in any of these formats provided authorship of VPS and LVPSG (the London Vulval Pain Support Group) is clearly acknowledged.

Reed BD et al. Prevalence and demographic characteristics of vulvodynia in a population-based sample. Am J Obstet Gynecol. 2012 Feb;206(2):170.e1-170.e9.

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## **VULVODYNIA**

# Do you have unexplained genital pain?

If all tests for infections come back negative but you still experience discomfort, burning or soreness, you may have vulvodynia.

## Unprovoked vulvodynia

is characterised by continuous burning, stinging, or soreness of the vulva.

## Provoked vulvodynia (vestibulodynia)

refers to pain experienced when pressure is applied to the vestibule (the entrance to the vagina) – for example, during sex or when inserting tampons.

Over a quarter of people with a vulva will have vulvodynia at some point in their lives.\* It can be distressing but treatment and support are available.

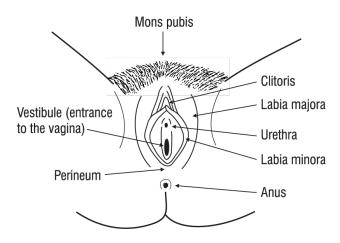
### Vulvodynia

**Vulvodynia** is the term used to describe the sensation of vulval burning, soreness or pain in the absence of any obvious skin condition or infection. Symptoms may be constant (*unprovoked vulvodynia*) or only evident on touch (*provoked vulvodynia*, also referred to as *vestibulodynia*).

Diagnosis must be made by a doctor knowledgeable about vulval problems. If you think you may have vulvodynia ask your GP, or local Genitourinary Medicine (GUM) clinic, for a referral. Ideally, you should do this as soon as possible, since a delay in getting an accurate diagnosis and treatment could lead to the pain becoming much harder to treat successfully in the long term.

Some doctors may not be familiar with the condition. This leaflet provides information, support and advice for people with vulvodynia and members of the medical profession.

### An illustration of the vulva, showing which areas may be affected



### **Unprovoked vulvodynia**

**What is it?** The condition is characterised by vulval burning and soreness, usually as a consequence of irritation or hypersensitivity of the nerve fibres in the vulval skin.

Symptoms are often constant and intensity may vary from mild discomfort to severe constant pain, which can interfere with sleep and sexual activity, and even prevent sitting or the wearing of trousers. Some people also experience related pain around the inside of the thighs, the upper legs and the anus. The burning sensation may be generalised over the entire genital area, or localised to just the clitoris (clitorodynia), or one side of the vulva only (hemivulvodynia). Itching is not generally a feature of the condition.

Usually there is nothing to see on examination as the problem lies with the nerve fibres themselves, which are not visible to the naked eye.

For a minority of people with unprovoked vulvodynia, back problems can cause spinal nerve compression and referred pain in the vulval area. In the majority of cases, however, the precise cause of the nerve damage, irritation or misfiring remains unknown.

How is it treated? Pain that originates from nerve fibres is best treated with drugs that alter the way the nerve fibres send their impulses to the spinal cord and create the sensation of pain. Pain-modifying drugs such as tricyclic antidepressants act in this way and have been used extensively to treat vulvodynia. (Note that they are not prescribed to treat depression in this case, but to dampen down the pain signals travelling along the nerves, and thus 'retrain' the nerves to function normally, i.e. without producing chronic vulval pain). The drugs are available from your doctor and examples include amitriptyline, nortriptyline and dothiepin. Sometimes drugs such as gabapentin or pregabalin are also used in the treatment of vulvodynia.

Chronic pain strategies such as mindfulness and stress management may also help relieve symptoms. Bland emollient creams and vaginal lubricants may also be of benefit. See the Vulval Pain Society's website (details overleaf) for more information.

## Provoked vulvodynia (vestibulodynia)

**What is it?** In 1987, American gynaecologist Edward Friedrich described a group of patients who experienced severe pain and discomfort of the vestibule area at the entrance of the vagina.

The pain experienced by people with vestibulodynia is variable; some are able to tolerate penetrative sex, whilst others find that even light touch or wearing trousers can be excruciating.

Often on examination of the vestibule there is tenderness to light touch. There may be red areas at the site of tenderness, but frequently the findings are 'normal'. Tests should be done to rule out infections and vulval skin conditions that may cause similar symptoms. Some doctors are unaware the condition exists and can often mistake it for thrush. Repeated use of topical anti-thrush treatments can make the condition worse.

It is likely that a number of factors cause vestibulodynia, but often no identifiable cause can be found. Some patients have a sudden onset of symptoms following a specific event: commonly a severe attack of thrush followed by anti-thrush treatment, or after giving birth.

How is it treated? People with vestibulodynia often benefit when treatments are combined. These can include skin desensitisation (making skin less sensitive) through massage, pelvic floor muscle physiotherapy, psychosexual counselling, and rarely, surgery (vestibulectomy).