

# Vulvodynia

### Introduction

This leaflet provides information about vulvodynia, its causes and symptoms and how the condition can be managed.

# What is vulvodynia? (vul-voh-dy-nia)

Vulvodynia is the medical term used to describe pain in the vulva or female genital area where the skin looks healthy and no cause has been found. This discomfort can be felt during normal touch such as sex, inserting tampons or from clothing.

# What are the symptoms?

Many women experience a burning, soreness and/or stinging sensation which can be felt in a specific place (localised vulvodynia) or over the whole vulva (generalised vulvodynia). Pain differs between women with this condition; it can vary from mild to severe.

# What causes vulvodynia?

We are unsure what the reason is for developing this pain, but current research suggests it is because of a nerve problem.

It is nothing you or your partner has done and it is not catching.

In some women the nerve endings become sensitive and interpret normal touch as pain (provoked vulvodynia). Giving birth, skin conditions such as eczema or lichen sclerosus and infections which can cause inflammation such as thrush, may trigger vulvodynia.

Some women will have pain that is not triggered by touch (spontaneous or unprovoked vulvodynia). We do not know the exact cause of this pain but some studies have shown links to other chronic pain conditions such as fibromyalgia or irritable bowel syndrome. In rare cases a back problem can send unwanted nerve signals from the spine to the vulval area.

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# How is vulvodynia diagnosed?

Following a discussion about your symptoms, the specialist may use a cotton bud to gently press on the vulval skin to see where the pain comes from. A swab may be taken to rule out any possible infection.

An internal examination may be needed to look for another condition called vaginismus – this is when pain can cause muscle spasm at the entrance of the vagina making sex painful or impossible (some women describe this as a barrier or wall).

# Are there any long-term problems?

Living with a long-term health condition, particularly a pain condition, can lead to low mood or anxiety. It is normal to have low interest in sex, difficulty reaching orgasm or lack of sensation - due to anxiety that sex may be painful. It is also normal to feel worried about what impact the condition may have on your relationships and sex life. When you have experienced pain for a long time your brain seeks to protect itself from activities which may cause pain, leading you to avoid these situations (which should be painless).

# Management options for vulvodynia

There are a variety of treatments and sometimes a combination of options are needed. Please do not worry if the first ones you try are not effective. Nerve conditions take time to respond to treatments and many of the options which have been shown to work need regular input from you.

### Vulval skin care

When the skin is over-sensitive it needs gentle treatment. Soaps, wipes and tight clothes can rub and irritate the skin. An emollient (moisturiser) can be used as a soap substitute - keeping the area clean, while gentle on the skin. The emollient can also be used as a barrier against irritants such as detergents on your clothes, sanitary pads or urine.

Do not douche, wash once a day only and use the emollient as a barrier throughout the day. If you wear pads because of incontinence or have difficulties inserting moon cups or tampons, unperfumed natural pads or reusable ones (made from bamboo or microfibre) are gentler on your skin.



#### **Moisturisers and lubricants**

Organic brands of these moisturisers such as Yes® and Sylk® (water based) are made from plants (non-hormonal). They help to maintain the natural environment of the vagina to reduce mild to moderate dryness. They can be bought online or in a pharmacy. Moisturisers are inserted into the vagina with an applicator and can be used every 1 to 3 days.

Yes<sup>®</sup> have produced an oil and a water-based lubricant; the oil preparation can thin latex and should not be used with condoms.

### **Physiotherapy**

There is strong evidence that physiotherapy, as a first-line treatment, can improve vaginismus and vulvodynia by up to 80%. The biggest improvements are seen after an 8 week course of weekly therapist sessions. Home exercises are best when done after a period of relaxation (or mindfulness). The sessions with the therapist may involve breathing exercises, stretching, massage and assessment of your back, tummy and pelvis (both external and internal vaginal examination) to look for areas of tight and tender muscles.

These exercises help to improve muscle function and sensation by relaxing tight areas. Part of your treatment may include the use of vaginal dilators.

### Vaginal dilators

www.gloshospitals.nhs.uk

These are cylinder shapes that come in different sizes. They help to improve confidence when having sex by reducing pain caused by anxiety. Relax for 15 minutes beforehand; using mindfulness or a warm bath. A numbing ointment (Lidocaine) can be used when you first start. Put a water-based lubricant on the dilator and insert into the vagina. Leave it inside for 5 to 15 minutes; there is no need to move it in and out. Try and use daily and move onto the next size after 3 to 4 weeks. It is normal to notice a little bleeding when wiping, during the first 2 weeks.



### Lidocaine ointment (5%)

This is an ointment which numbs the nerves when you put it on the skin. You should apply this cream each night for 6 weeks (even if the pain improves) before attempting sex. During this time, you can also put the ointment on 15 minutes before sex but remember to wipe it off beforehand as it can stop condoms working or may numb your partner's skin if not using condoms.

Research suggests pain and ability to have sex is improved by 50 to 70%. Long term (using for more than 6 weeks) it can cause skin irritation so if your pain does come back there are other treatment options available.

### Pain modifying medication

These medications can reduce pain signals from your nerves and are given in tablet form. They are started at a low dose and are slowly increased to reduce the side effects. It can take 8 weeks before the pain starts to improve. You should continue the medication for 6 months to get the best effect and slowly reduce when no longer needed.

- Amitryptyline or Nortriptyline 50% of women with vulvodynia report that their symptoms settle. Side effects of these medications can include tiredness, dry mouth, feeling sick, loss of desire, constipation and difficulties passing urine.
- Gabapentin and Pregabalin 60% of women report that their vulvodynia symptoms settle. Side effects can include dry mouth, blurred vision, tiredness, feeling sick, increased appetite, headache and mood changes - these improve with time.
- **Duloxetine/Venlafaxine** Some patients find these medications helpful. They tend to have less side effects but women can experience headaches, feel sick or dizzy, have a reduced sex drive or insomnia when first using.

## Psychosexual counselling

Lack of desire due to chronic pain can continue, even after the pain has improved with treatment, if these feelings are not talked about. Specialist counselling can help you recognise and discuss these feelings and find ways to maintain a close relationship, leading to improved desire and arousal.



Mindfulness methods may help you focus on being with your partner and letting go of negative or distracting thoughts.

# Other management strategies

- **Stop smoking** smoking reduces how well your skin heals and speeds up harmful changes.
- Low oxalate diet avoiding beans, chocolate, coffee and berries can improve pain.
- Reduce stress stress can make our ability to cope with health conditions more difficult. Changes in your daily life such as exercise (yoga, swimming, running) and addressing sleep habits can help you cope with the physical and emotional effects of vulvodynia.
- Acupuncture can reduce pain by 50% in women with unprovoked vulvodynia after 5 weeks of treatment. Very thin needles are inserted on specific points in the lower legs, feet, hands and lower tummy. How long the effects last and whether it helps provoked vulvodynia is unknown.
- Cognitive Behavioural Therapy (CBT) when upsetting symptoms go on for a long time, our minds can stop us thinking about pleasant things and focus on negative thoughts. CBT helps you to cope with your symptoms through breathing exercises, good sleep habits and by recognising negative thoughts and becoming less upset by them. It can be completed online or as a group course over 4 to 6 weeks. Sexual pain is reduced by 50% and the benefits are still reported 2½ years later.
- **Botox injections** this medication blocks the release of pain signals and can be considered if other therapies fail in women with **provoked vulvodynia**. Up to 70% of women have some benefit and the effects can last up to 3 months. Not all centres offer this.



### Resources

### **Vulval Pain Society**

www.vulvalpainscoiety.org/vps

### **National Vulvodynia Association**

www.nva.org

### **British Association of Dermatologists**

www.bad.org.uk/patient-information-leaflets/vulvodynia

# British Association of Dermatology - 'Care of Vulval Skin' leaflet

https://www.bad.org.uk

### Silicone Vaginal Dilators:

https://www.soulsource.com/

### Yes! Intimate lubrication and Moisturisers

www.yesyesyes.org

### **Physiotherapy**

https://www.csp.org.uk/public-patient/find-physiotherapist

**Mindfulness**: 'Mindfulness for busy people' by Michael Sinclair and Josie Seydel

## **Psychosexual Counselling**

https://www.ipm.org.uk/

### **Cognitive Behavioural Therapy**

https://www.cbtregisteruk.com/

## **British Acupuncture Council**

www.acupuncture.org.uk

### **Headspace**

https://www.headspace.com/

#### Calm

www.calm.com/

#### Meditainment

https://www.meditainment.com/

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# Making a choice

# **Shared Decision Making**

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



# **Ask 3 Questions**

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

- 1. What are my options?
- 2. What are the pros and cons of each option for me?
- 3. How do I get support to help me make a decision that is right







AQUA https://aqua.nhs.uk/resources/shared-decision-making-case-studies/