

Living with Vulvodynia

This leaflet is for people who have been diagnosed with vulvodynia, who are currently receiving or have received medical treatment

As well as the physical effects of vulvodynia, some people find that the experience of this condition can have an emotional impact. This leaflet provides some information about the ways people can be affected, some strategies that may help, and what further support is available. The first part describes some of the common reactions to vulvodynia, and how it can affect different parts of your life. Not all of these will apply to everyone. From page six onwards, it offers some ideas about how to manage some of the difficult thoughts and feelings that can accompany living with vulvodynia, and will help you think about how to make choices that may improve your quality of life.

There is a lot of information in this booklet and it may be helpful to read it several times, in small chunks, or with a friend or family member to get the most from it. You might wish to read part of it for now, and then come back to it at a later stage, whenever you feel ready to do so.



Contents

	Page number
1 Introduction	2
What is Vulvodynia?	2
What causes Vulvodynia and how is it treated?	
2 The effects of Vulvodynia	3
Physical effects	
Emotional effects	
Impact on relationships	
The effect of Vulvodynia on your thinking	
The effect of Vulvodynia on your actions	
“Vicious cycles” and “virtuous cycles”	
3 Coping with Vulvodynia	6
Tackling your thoughts	
Using a mindful approach	
Dealing with relationship issues	
Tackling unhelpful behaviours	
Dealing with low mood	
Dealing with worry and anxiety	
Dealing with shame	
The mind/body link and using it to your advantage	
4 Asking for help	15
5 Where to find more support and information	16

Introduction

What is Vulvodynia?

The term vulvodynia is used to describe persistent pain in the vulva (the female genital area) in the absence of any visible abnormality or identifiable cause.

It is thought that the pain is a result of a nerve problem which means the nerve fibres become overly sensitive or irritated and send abnormal signals, which are felt as a pain sensation. In this way, the vulva can become like an oversensitive smoke detector, where the slightest detection of touch can set of an alarm to the brain signalling danger which results in pain. It can also happen following surgery to the vulva, particularly if this has resulted in scarring.

If the symptoms are continuous, the condition is classified as **‘unprovoked vulvodynia’**. If the symptoms occur when pressure is applied, the condition is classified as **‘provoked vulvodynia’**, also known as **‘vestibulodynia’** (the entrance to the vagina is known as the ‘vestibule’). This could happen during sexual intercourse, from touch, when a tampon is inserted or even when sitting for a prolonged period or from wearing tight fitting trousers.

The location, constancy and severity of the pain vary among women. Some women experience pain in only one area of the vulva, which is known as **‘localised’** (for example the left side of the vulva or near the clitoris) while others experience pain in multiple areas, which is known as **‘generalised’**.

A diagnosis of vulvodynia is given when all other diagnoses have been discounted through examination and investigation. Some other potential causes of these symptoms include persistent vaginal thrush,

sensitivity to a cosmetic or medical product, a drop in oestrogen, a recurrent herpes infection or as a result of skin conditions known as lichen sclerosus or lichen planus.

As a condition, vulvodynia remains poorly understood by the medical world and little is known about its origin and how to treat it effectively. However, there are a number of treatment options, which may be offered to you including; anti-depressants (not to treat low mood but to alter pain perception), surgery, physical therapy, (including use of dilators, pelvic floor muscle training and biofeedback), sexual therapy or psychosexual therapy, and holistic treatments such as stress management, psychological therapies, changes to diet, and acupuncture.

It can be frustrating since there is no 'one-size-fits-all' solution and it may be that a number of treatments or combination of treatments are tried before discovering a regime which works for you.

The effects of Vulvodynia

Physical effects

As explained, the precise characteristics of vulvodynia may vary from person to person, but what is very certain is that the main physical effect is the experience of pain. This pain sensation is described differently by different patients. Some report a burning sensation, others as a stinging or 'knife-like' pain. The symptoms are often constant and intensity can vary from mild discomfort to severe constant pain which can interfere with sleep and sexual activity.

Emotional effects

We recognize that the ongoing pain and discomfort that accompanies vulvodynia can have a significant impact on your emotional wellbeing. Initially, when you receive the diagnosis, you may experience a sense of relief since the problem has been recognized and named. However, we also know that you may experience a number of difficult emotions whilst living with vulvodynia. We have described some of the common ones below -

Low mood or depression: Living with a chronic health condition can increase the likelihood of experiencing low mood or depression. This can mean experiencing a variety of symptoms such as feeling sad or numb, hopeless about the future, having negative thoughts about yourself, other people or the world, feeling lonely, or as though you are carrying the burden of the disease without support.

If you think you are experiencing depression and have had thoughts that your life is not worth living, it is important to tell a healthcare professional, visit your GP or attend A&E, particularly if you think you might act on these thoughts.

Worry and anxiety: You may be concerned, worried or frightened about what the condition means for the future of your relationship and sex life. Many patients find their mind constantly circling with questions such as 'is there permanent damage?' 'will this go away?' and 'will I ever feel better and the pain stop?', which can be difficult to get definitive answers for following a diagnosis. These thoughts may cause you to constantly check to see if there are any changes to your vagina and may lead to a preoccupation that prevents you from engaging in certain activities.

Shame: Some people report a difficult route to diagnosis due to the number of professionals that it may have taken to be seen before a diagnosis is given and the intimate location of the pain. As diagnosis often comes from a process of elimination of other illnesses, it can feel like it is not being taken seriously and or that you are being told it is 'all in your head'. By not feeling properly understood, it can be difficult to relay your worries or concerns to partner or potential partner as this may feel embarrassing or shameful in some way. The impact of vulvodynia on your relationship is addressed in more detail later in this leaflet.

All of these feelings are very normal and it is natural to experience some or all of these feelings at different stages of illness as you continue to process new information. It is possible that they will come and go over time and that many will go away by themselves as you begin to come to terms with your condition. However, if they persist then there are a number of different things you can try which may help.

The effects of vulvodynia on relationships

Typically vulvodynia has a profound impact on interpersonal relationships. Pain can make penetrative sex very uncomfortable and sometimes as a consequence of vulvodynia, women can have 'vaginismus' which is involuntary contraction of muscles which makes penetration either very painful or impossible.

Some woman experience lack of or low interest in sex, may not experience physical sexual excitement, do not feel sexually turned on or have pleasurable sexual feelings when engaging in sexual activity, difficulty reaching orgasm, genital pain or discomfort during or shortly after, or experience persistent and unwanted sexual arousal in absence of sexual interest.

It can be difficult to talk to an existing partner or when thinking about starting a new relationship about the diagnosis of vulvodynia and what that might mean for your sex life. Women have reported being embarrassed or ashamed of the issue and can start to distance themselves from their partner.

It is important not to despair if you find yourself experiencing difficulties in your relationship as a result of vulvodynia. Help is available and more information about dealing with relationship issues is given later in this leaflet.

The effect of Vulvodynia on your thinking

The way we make sense of our experiences depends a lot on how we think about them. We can have positive 'glass half full' thoughts which may be really helpful and allow us to get through difficult times. However, often in times of stress, our minds come up with scare stories instead, which can be less helpful. Often there is a noticeable pattern to these negative thoughts which are known as 'unhelpful thinking styles'. Everyone can fall into these patterns at times, and they are often so automatic, that they happen beyond our awareness. Thoughts can also be balanced or unbalanced and do not necessarily appear wholly positive or wholly negative. Sometimes just being able to notice and recognise these thinking patterns can be useful. Some examples of such thinking styles are set out below:

Thinking Style	Examples commonly associated with feeling low or depressed
Self-criticism and labelling	"I cannot seem to snap out of this low mood and stay positive. I am a failure"
Self-reassuring language ('shoulds, oughts, musts')	"I should be able to cope with this and I ought to be able to continue living a normal life. I must get on top of this"
Black and white thinking	"Nothing is improving, I may as well give up"

Thinking Style	Examples commonly associated with feeling anxious or worried
Thinking the worst	"I won't be able to have children"
Predicting the future	"I won't be able to have sex with my partner and he will leave me"

Thinking Style	Examples commonly associated with feeling embarrassment or shame
Mind-reading	"My partner is not going to want to have sex with me because there's something wrong with me"
Black and white thinking	"It always going to hurt to have sex, there's no point in even trying"

You might identify with some or all of these, or be able to think of your own individual examples.

The effect of Vulvodynia on your actions

Some things you do will have a positive effect on how you feel physically and emotionally, including maintaining a good diet, exercising, maintaining a consistent sleep routine and making time for activities you enjoy such as hobbies and socialising. Other things like smoking, using illicit drugs, drinking too much alcohol, or spending a lot of time playing video games or watching TV can seem to offer immediate relief, but make you feel worse in the long-term if they serve to avoid doing other activities that might improve wellbeing.

You may find that you start avoiding things because of feeling anxious, low or physically uncomfortable, for example you may put off seeing your medical appointments or stop doing things you used to enjoy. This can make life seem easier in the short term because you do not have to face the situation you fear, overcome the feeling that you 'can't be bothered' or tolerate the unpleasant physical symptoms. However, this can be unhelpful in the long term and lead you to feeling stuck. For example, putting off your hospital visit due to fear can lead to more anxiety because you never find out if your fears come true. Similarly, cancelling plans with friends because you feel low can make things worse because you do not get the chance to experience fun, pleasure and a sense of achievement.

Vicious and Virtuous Cycles

The sections above describe the ways that your body, thoughts, feelings and behaviours can be affected by vulvodynia. You may have noticed how these things are all closely linked, which means a change in one area can have a knock-on effect in another area. For example, the thoughts we have about a situation can affect how we feel physically and emotionally, as well as what we choose to do. This relationship can be understood in the form of a cycle and whilst some cycles can interact in positive and helpful ways ('virtuous cycles'), others can interact in negative and unhelpful ways ('vicious cycles'). Below is one example of a vicious cycle:

Anna was diagnosed with unprovoked vulvodynia and was finding the constant uncomfortable pain irritating so she did not leave the house unless it was an emergency. Anna soon felt bored, hopeless and isolated. After a few weeks when she did try and go out to visit friends she felt anxious and her experience of her pain increased. She thought to herself "if it's just going to feel worse when I go out, there really is no point". This meant Anna did not go out again and felt more lonely and depressed.

Coping with Vulvadynia

It is important to remember that while it might not be possible to be free from pain and discomfort in vulvadynia, you can find ways of coping with it, getting on with your life, and feeling better.

Tackling unhelpful thoughts

Thoughts enter our minds constantly throughout the day, and can be pleasant, unpleasant or neutral. You could think of the mind as like a storyteller or narrator which is constantly commenting on what is happening around us. Often the mind comments in helpful ways, drawing our attention to interesting or pleasant things, reminding us of happy memories from the past or reminding us of things we have planned in the future. However, sometimes during times of stress, the mind can be less helpful and instead, might draw our attention to unpleasant things, remind us of negative memories from the past or make scary predictions about the future. Although it can seem as though these thoughts represent reality and are 100% truthful, this is not always the case. It can be hard to remember that thoughts are just thoughts, and not facts, which is why we can get into difficulties.

The first step in tackling unhelpful thoughts is to notice what they are, perhaps by trying to pay attention to what your mind is saying (or 'narrating').

The next step is to step back from your thoughts and question them, since they are often based on the wrong assumptions. You could ask yourself the following questions:

- What makes me think this thought is true?
- Is there anything to suggest this thought may not be true?
- Is there another way of looking at this?
- Based on the evidence for and against this thought being true, what is the most logical or balanced alternative perspective?
- If a friend who I cared deeply about had this thought about themselves or their situation, what would I say to them?
- What are the costs and benefits of thinking this way?

While challenging thoughts in this way may not stop them coming into your mind, it could help you feel less upset or distressed by them.

Here is an example of how this method could be applied to Anna's situation:

Anna was in pain so she decided to stay at home. She soon felt bored, hopeless and isolated. After a few weeks when she did try and go out to visit friends she felt anxious and her experience of her pain increased. She thought to herself "if it's just going to feel worse when I go out, there really is no point". However, she was able to notice that this was an unhelpful thought and so decided to question how true it was. She asked herself what she would say to a friend in this situation and thought she might say "I know you are in pain and this is distressing for you but you might have a chance of feeling a bit better if you get out and see the people who you enjoy spending time with. Perhaps you should try and go out for an hour at first and see how you get on. You could then build it up over time and gradually build up your confidence". This helped Anna to construct an alternative, more balanced and helpful thought, which led to a plan to try a different behaviour (going out to see friends). Gradually she began to go out more and more and gain a better understanding of her ability to manage the pain when away from the house. This in turn helped her to feel less hopeless and low in mood.

Using a mindful approach

If the above strategy does not work for you, or you are finding it hard to name your thoughts, another method you could try is to apply a mindful approach. This is a way of becoming more aware of our mind and body right now, and can help us detect certain feelings, unhelpful thoughts or images. Often we can get caught up in reacting to thoughts or feelings automatically, without a successful outcome. Instead, mindfulness encourages us to take a curious stance towards our experiences, including thoughts, feelings and sensations. It teaches us to simply notice them without judgement or trying to change them. To start with, you could try following these simple steps:

First notice the thought that has popped into your mind

Try not to judge the thought as good or bad, just notice it

You could thank your mind, the storyteller, for its contribution to your day

Then ask yourself, is this thought a helpful one? If so, then perhaps pay attention to it and act on it

If it is not helpful, and your experience tells you that these thoughts make you feel bad and keep you stuck, just observe the thought instead of reacting or responding

You could try seeing the thought in your mind's eye being a headline on a newspaper that tends to print exaggerated stories

Then let the thought drift away, like leaves on a stream, or cars passing by outside your window

Being mindful of your experiences is a very different way to our natural way of paying attention and can take practise. There are many good books, CDs and apps for mindfulness if you think this approach might be helpful for you.

You can also find some mindfulness recordings at:

<http://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Self-help-materials.aspx>

Tackling unhelpful behaviours

Sometimes it can feel too difficult to notice and challenge our thoughts and you may find it easier to work on tackling unhelpful behaviours to start with instead. You may have received lots of advice about eating a balanced diet, establishing a good sleep pattern, exercising regularly, avoiding drugs and alcohol, and taking medications as prescribed. Often it can be easier to start doing new, more helpful behaviours, than to try and stop doing unhelpful ones.

To do this, try to ask yourself what is important to you and what your values are (e.g., family, friendships, your health, your work or your hobbies). Then try to do something most days that keeps you moving in the direction of what matters to you most. You may need to try out new approaches if your old strategies don't work.

Do things you enjoy and that bring you fun, pleasure and laughter. This could mean meeting a friend who makes you laugh, watching a repeat of a comedy show or making time for things you relish such as watching sport or soaking in the bath. Also, try to do things that you get a sense of achievement from.

If you want to make a change, such as taking steps to quit smoking or lose weight, try to set a specific goal, write it down and reward yourself once you have achieved it. If you have a setback, do not give yourself a hard time but remind yourself that setbacks are normal and remain curious about what went wrong so you can think about what to do differently next time. If you think it was unrealistic, reset your goal and re-commit to it, rather than giving up. If you have several barriers which you struggle to overcome, try using a 'problem-solving' approach (see **IMPARTS** leaflet, *'Problem Solving for People Living with Health Conditions'*).

Dealing with relationship problems

Sexual dysfunction in women with vulval pain is common, but not inevitable. When it occurs, it is important for the woman (and her partner, if she is in a relationship) to be aware that sexual problems can be treated, and that help is available. When sexual problems are ignored, the woman may find herself in a position where (months or years later) her vulval condition has improved, with or without treatment, but in the meantime she has lost her sexual desire, and may even be experiencing more general relationship difficulties as a result of long term sexual avoidance.

A psychosexual therapy for couples known as 'sensate focus', pioneered by Masters & Johnson (1970) is very useful in the treatment of a range of sexual problems. In essence, the couple are instructed to set 'protected' time aside on a regular basis during which they are encouraged to explore and touch each other in a mutually pleasurable way. Initially, this starts off with touching only the non-sexual parts of the body, and as the couple progress, the sexual parts are included gradually. Throughout all this time, there is a 'ban' on sexual intercourse, in order to allow the woman to relax and enjoy 'safe' touching without tensing up (physically and/or emotionally) at the thought of 'what might follow' (i.e. penetrative intercourse and pain). It is also important for the couple to alternate between being the 'active' and 'passive' partner during each pleasuring session, and to take it in turns to initiate (who goes first as the 'active' one, i.e. the one to start touching/stroking/massaging their partner). Gradually, over a number of weeks, the woman can hopefully move from safe, physical, non-sexual closeness to sexual/erotic intimacy and ultimately to sexual intercourse, whilst experiencing an increase in libido, arousal, vaginal expansion and lubrication. There is more information at the end of this guide on how to access psychosexual couple's therapy if this is something you wish to pursue. It is also possible to try elements of this outside of therapy without the guide of a professional as plenty of information about 'sensate focus' is available online.

For women with vulval pain during penetration, 'sensate focus' psychosexual therapy with her partner is best combined with pelvic floor exercises, biofeedback, and the use of graded vaginal dilators to use during additional solo practice. Vaginal dilators can be purchased online and are plastic objects that can be used to gradually stretch the vagina to widened and lengthen the vaginal passage. They come in a range of sizes to gradually increase stretching over time. Women who experience painful sex are likely to suffer from impaired libido and arousal, as described earlier. Therefore, concentrating more on foreplay and non-penetrative forms of sexual pleasuring should help to increase enjoyment and reduce pain. 'Sensate focus' is a good way of 're-educating' partners in the art of sensuous pleasuring without merely perceiving this to be a 'means to an end'! However, where penetrative intercourse does occur, it is important to use also plenty of additional vaginal lubrication (e.g. Senselle, Astroglide, Yes!).

Dealing with low mood and depression

Feeling low in mood or depressed is common when you have been experiencing pain, particularly if the pain has kept you away from things you usually enjoy.

When you are depressed, you may believe that you are helpless and alone in the world; you often blame

yourself for all the shortcomings that you think you have. At the bottom of this, you feel negative about yourself, about the world and about the future, which means you tend to lose interest on what is going on around you and do not get any satisfaction out of the things you used to enjoy. It can become harder to make decisions or carry out simple tasks as you did before. You also may not be sleeping or eating well. Fortunately, once again there are a number of things you can try out which have been shown to help people when they feel depressed.

Challenging gloomy thoughts

As described earlier, it can be helpful to recognise the unhelpful thoughts you are having about yourself, others or the world e.g., 'I am useless', 'no one is caring' or 'the world is a horrible place'. Everyone has these thoughts from time to time, but for people who are depressed, they tend to be around a lot more of the time.

Try to remember that these thoughts are automatic and are often not rooted in any logic or reason. They therefore serve no purpose than to make you feel bad since they are unreasonable and unrealistic. When people are feeling low they can become trapped in patterns of distorted thinking such as over-generalising, mind-reading, black-and-white thinking or discounting the positive. Ask yourself whether any of these are around for you.

You could try writing down your negative automatic thoughts and opposite each one, write a more balanced, positive thought, for example:

Negative automatic thought	Balanced thought
"Living with this illness means I can no longer enjoy having sex".	"Although I may experience some discomfort during sexual intercourse, there are still lots of other sexual act I can try that might be pleasurable".

Often people who are depressed tend to forget important details and think in more general statements such as, 'I have never been good at anything'. Try and train yourself to remember specific details so that good times and experiences are easier to recall. A daily diary can help with this, or you could list past achievements or memories of pleasant experiences.

Changing what you do

Research tells us that gradually increasing activity over time can be helpful for overcoming depression. This could mean making a list of things to do, mixing with other people, joining in activities, taking exercise, or simply doing anything you enjoy.

Make a plan or a schedule of your activities for the week, starting by filling in the things you have to do, such as work, making appointments, doing housework or preparing meals, and then plan other activities in the time you have free.

Try to find a balance between activities of pleasure (e.g., seeing a friend, having a bath, reading, watching a film), and those of mastery or achievement (e.g., exercise, shopping, decorating, gardening, paying bills, writing a journal). With regards to exercise, you may find it easier to build this up gradually, starting with small steps, especially following an operation, as muscles take time to heal up. Also, with tasks you have been putting off, try breaking them down into smaller stages and tackling them one by one.

Take care of yourself physically, this means paying attention to your sleeping and eating patterns. If your mind is busy, it could be having an impact on your sleep.

Unhelpful coping behaviours can include drinking alcohol, taking drugs or drinking caffeine. Try to avoid doing any of these if you can (speak to someone if you have a problem giving up).

Think about what really matters to you, i.e., your values. Try to do something most days that keeps you moving in the direction of these values.

Dealing with worry and anxiety

We all experience anxiety from time to time, since it is a normal response to situations that we see as threatening, such as a near miss with a car in the street. A certain level of anxiety can even be helpful, for example if we want to perform well or cope with an emergency. As a result of having a chronic illness, it is natural to feel anxious about your recovery, your future health, work, family life or maybe other things. However, it can become a problem if it stays around for a long time since it can make physical symptoms worse, or stop you doing things you usually would enjoy.

The physical sensations associated with anxiety are very similar to those of anger, since it is also a result of the body's instinctive 'fight or flight' response, mentioned earlier in this leaflet. These symptoms include a racing heart, increased breathing rate, a dry mouth, sweating, tingling and feeling dizzy. The list of tips below could help you to cope with both the thoughts accompanying your anxiety, and with the physical sensations. Remember that anxiety itself is not dangerous or harmful, it is just a feeling.

Coping with anxious thoughts

Again, the first step towards tackling unhelpful anxious thoughts is to recognise what these are. You might want to keep a diary of the times you are feeling anxious and what types of thoughts are running through your mind (these can be difficult to pinpoint since they are often very fleeting and automatic).

If it is a realistic worry or problem that is causing you anxiety, try to problem solve it by defining what the worry problem is (or what the main problem is first), then ask yourself if there is something I can do about it, or not. If there is something you can do about the worry or problem, you can write a list of all the possible solutions. You can then ask yourself if there is anything I can do about it right now or not. If there is something you can do about it now, then get on and do it. If there is not something you can do about it right away then make a plan of when you can do something about it and make sure you have a reminder to implement the plan (see **IMPARTs** leaflet, '*Problem Solving for People Living with Health Conditions*' for more detail).

If the worry is about something you cannot control, you might wish to try using mindfulness (see section above) to help you to tolerate the anxiety, and let it fade away, or you could use some of the tips outlined in the next section below.

If the worry is in relation to your illness, it might be something you want to get checked out straight away (e.g., a change in your bodily symptoms), or make a note of to ask at your next appointment (see the 'asking for help' section below).

If your anxious thought is about what your physical symptoms mean (e.g., 'I am dizzy which means I will faint'), try to ask yourself whether this thought is realistic, and come up with a more balanced thought (e.g., 'I have felt dizzy many times before and not fainted. When I fainted, it felt different'). This may take some practise but it will get easier with time!

Be kind to yourself and try not to block out the worries but accept they are present. Do not criticise yourself for having these worries but try to be kinder to yourself. You could ask yourself 'what would I say to someone who I cared deeply about who was going through this?'

Do something different

Try to be mindful of unhelpful behaviours that you might be doing to cope with anxiety, for example; avoiding others or activities, or drinking excessive amounts of alcohol, or using drugs. If you are avoiding certain things because of anxiety, try to tackle these fears in a graded way.

If you are afraid of a certain situation, try to stay in that situation and wait for the anxiety to subside. It usually will come down after a few minutes. For example, if you are anxious about going out, a walk to the shops might be a first step. Although you might feel anxious, if you walk to the shop and stay there for a few minutes the anxiety will usually subside. This can then be extended to another shop a few minutes further away. Eventually you should learn that the situation is not to be feared and you will not have the same anxious reaction as you have in the past. Even if you do start to feel anxious in a new situation, you will have learnt that the feeling of anxiety will subside within a few minutes.

In order to reduce physical symptoms of tension or anxiety, you might want to try relaxation techniques such as controlled breathing, or mindfulness. Controlled breathing is a method of taking normal breaths that are not deeper than usual, using the lower chest whilst keeping the upper chest and shoulders relaxed at the same time.

An example of a controlled breathing exercise:

1. Place your hand lightly on your upper chest and the other on your abdomen just below where the ribs divide.
2. Take a normal breath in through your nose and feel the hand on your abdomen rise up and out.
3. Now breathe out quietly through your mouth and feel the hand on your abdomen sink down and in. The hand on your upper chest should hardly move.
4. Breathe at a rate that is comfortable for you.
5. Now, when breathing, try to make your breathing out last twice as long as when you are breathing in (it will help to count slowly as you breathe in and out).

Some people can relax using other methods such as exercise, listening to music or reading a book, or you might want to find a relaxation or yoga class to try (ask your nurse or doctor for recommendations or search online).

Distraction can also help you take your mind off your symptoms, or keep your mind occupied whilst your anxiety symptoms begin to fade (you will need to distract yourself for at least 3 minutes before this happens). Try focussing on things around you, study your surroundings in detail or listen to other people's conversations. This can help re-focus your mind off your worries. You could also try doing another activity which you find pleasurable or masterful, in order to distract yourself from worrying.

Dealing with shame

Feeling embarrassed or ashamed is a normal emotion that we all experience at times.. However when shame stops us from seeking medical help on grounds of finding the interaction with medical professionals too difficult, as has been reported with some gynaecological issues, then it becomes counterproductive. Similarly if feelings of shame is preventing you from having conversations with your partner or potential partner about the difficulties you may experience sexually, this can bring distance in a relationship or stop it from starting at all. Again this means that these feelings of shame are not

helping, but are negatively impacting on emotional wellbeing.

Taking a compassionate approach with ourselves can help to overcome feelings of shame and self-criticism. Compassion is described as a *deep sensitivity to the suffering of the self and others and a commitment to try to alleviate it*. A compassionate person would therefore need to be warm, strong, non-judgemental and wise in order to meet the criteria of having compassion and would act in a way that is consistent with these qualities. This can be a difficult approach to take with yourself in times of distress, especially when you are feeling the powerful emotion of shame. To overcome this, it can be helpful to generate an image of an *ideal compassionate other*. The image may then be able to support you and guide you in difficult situations when you are feeling particularly high in shame.

Here is an exercise to support you to create an *ideal compassionate other* image

Sit comfortably, with your feet on the floor and your back in a straight posture and gently focus on your breathing. Follow the breath as it comes in and follow it as it comes out.

Start to think about what an ideal compassionate image might look like, let the image immerge in your mind and gently notice what comes up. Remember that the image must have the qualities of wisdom, warmth, strength and non-judgement.

Some questions to ask yourself might be:

- What would I want my image to be; old or young, male or female, human or non-human?
- What would their tone of voice be?
- How would they relate to me?
- Do they make me feel safe and cared for?

Once you have generated a compassionate image that you are happy with and it has all the required qualities, you can use the image to support you in difficult and shame provoking situations.

- How would the image support you to go to your medical appointments? What would they say about the appointments? What would their tone and support be in the room when you were there?
- What would the image say to you when taking about the impact of vulvodynia on your sex life? What would they think about the struggles you have been experiencing in your relationship?
- How would the image help you to approach those difficult days when you do not want to leave the house? How would they support you to do the things you need to do to improve your wellbeing?

Using mind-body link to your advantage link to your advantage

The brain and the body are constantly sending messages to each other. These messages tell the brain and body to make changes and adjustments to the way they are working. For example, if your eyes told your brain a car was travelling towards you at speed, it would send a very fast message to the body to step back out of harm's way. Similarly, if your stomach was empty and your body needed fuel, your brain would listen to that message and send you in search of food. So, the mind and the body are in constant communication to keep you healthy.

An example of this close relationship between the mind and body is the 'Fight-Flight' mechanism. This alarm system developed to keep us safe from danger, like the threat of predators for example. It is triggered when you feel threatened and it makes your body get ready for a fight or for running away (e.g. by making your heart beat faster and your muscles tense up). These physical symptoms are the result of the release of stress hormones in the body, such as cortisol and adrenaline. This worked really well

when there were predators around. Unfortunately, it is less helpful for modern day threats. Things like money worries or fears about the future can trigger this 'fight or flight' response, even if it is not that helpful for solving the problem.

The mind-body link does not only have bad effects on our physical and emotional state, it can also have good effects. You may recognise some of the examples below.

Relaxation

When you get a chance to relax, such as having a bath, sitting in the sun, listening to a calming piece of music or practising meditation, you may notice changes in your emotional state such as feeling less tense and more at ease. There are also changes that happen in your body such as your heart beating slower, your breathing slowing down and your blood pressure going down.

We have a selection on mindful meditation exercises available to download on the **IMPARTs** website at: <http://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Self-help-materials.aspx>

Exercise

Many runners and other athletes talk about feelings of physical and emotional well-being during and after exercise. You can feel this after lots of other activities as well, such as walking, going up the stairs or going to exercise classes. It is thought that chemicals called endorphins, which your body produces when you exercise, are what make you feel happier.

Positive events, pleasure and achievement

When positive things happen such as getting good news, laughing with friends or being meeting with friends or family after a time apart, you usually feel happier and more at ease. During these times, you may also feel more physically alert and active rather than sleepy and sluggish. The same can happen when you do activities you enjoy or something that gives you a sense of achievement. These examples show the powerful effect of positive experiences on both your mind and body.

Asking for help

Where to get help in your relationship

Sexual therapy is available privately and on the NHS. In terms of finding psychosexual therapists with expertise in vulval pain syndrome, these may well be linked to NHS Departments where specialist vulval clinics are being offered (e.g. Departments of Genitourinary Medicine, gynaecology/women's health care departments, dermatology clinics), in which case the responsible medical consultant should know whom to refer on to. Access to physiotherapists specialising in women's health may also be advised by hospital consultants. A number of chartered clinical psychologists who specialise in sexual health do provide expert input to NHS clinics (primarily in England), where women with vulval pain are being seen.

A list of accredited and registered sexual and relationship therapists is available from **COSRT (College of Sexual and Relationship Therapists)**, PO Box 13686, London SW20 9ZH, T 020 8543 2707). COSRT-listed practitioners work in the NHS, privately, in other appropriate services, or in a combination of such settings.

Approximately 10 per cent of Relate (formerly Marriage Guidance) counsellors have also got additional training in psychosexual therapy. Their number can be found in the telephone directory, and self-referrals

are accepted. As a registered charity, the service relies on donations from clients (approx. £20-£30 per session), although this can be negotiated (and reduced) depending on individual circumstances.

Further help for sexual and/or relationship difficulties, or help with acute and chronic pain, can be obtained from your local Department of Clinical Psychology. Referral to a qualified clinical psychologist is usually necessary via the patient's GP or hospital consultant.

Where to find more support and information

Vulval Pain Society

www.vulvalpainsociety.org/vps

National Vulvodynia Association

www.nva.org

British Society for the Study of Vulval Disease

www.bssvd.org

International Society for the Study of Vulvovaginal Disease

www.issvd.org

NHS information page on vulvodynia

www.nhs.uk/conditions/vulvodynia/Pages/Introduction.aspx

Amielle Comfort Dilators

www.amazon.co.uk/Amielle-Comfort-Vaginal-Dilators-Full/dp/B0045XBSWC

Yes! intimate lubrication

www.yesyeyes.org

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With special thanks to Dr Sarah Walsh (Consultant Dermatologist, King's College Hospital) for consulting on this leaflet with her professional knowledge and the patients that consulted on this by sharing their experience of living with vulvodynia.

King's Patient Advice and Liaison Service (PALS)

This is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer - staff will be happy to direct you.

Tel: **020 3299 3601**

Email: **kch-tr.pals@nhs.net**

The full range of IMPARTS booklets can be found at:

www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Self-help-materials.aspx



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