Sex and chronic pain

Persistent pain can impact on lots of areas of life such as work, exercise, socialising and mood. This leaflet is designed to give advice to people who have found it more difficult or have had to give up sexual activity because of pain

It is often a difficult topic for people to communicate about and health care professionals may not always feel skilled and confident in addressing sexual difficulties. For individuals who are not in a relationship, they may lose their confidence and assume that a romantic relationship is now out of the question. Existing relationships can suffer, particularly if partners find it challenging to maintain intimacy. Studies show that individuals with chronic pain are more likely to experience difficulties with sex than those without pain, and to be anxious about sexual activity.

Myths about sex

There are lots of 'ideals' or myths about sexual activity, which you are constantly exposed to by the media (newspapers, magazines, TV, films etc.). It is really difficult not to take these ideals on board and you may hold them 'in your head' as standard which your sex lives *should* live up to. Sometimes having these ideas in your head can make maintaining an active sex life alongside chronic pain even more challenging than it would be anyway. Some commonly held myths are:

- Sex should be spontaneous – you should never have to plan it or talk about what you like.
- Sex should be adventurous and different every time.
- Sex is only for young, beautiful and able people.
- Everyone else is having sex frequently – at least three times a week.
- If a partner isn't sexually satisfied, they will look elsewhere for sex and intimacy.

It is easy to see how these ideas add to the pressure which you all feel, to have a 'perfect' sex life. If you are finding sex painful, then these myths of how sex 'should' be can lead you to feel that it is not even worth trying, as you are so far from this 'ideal'.

Bad experiences with pain

Over time, unpleasant sensations before or during sex, or a flare-up of pain afterwards, may mean that, like with any other activity, you reduce how often you do it, or avoid it altogether. If you continue to be sexually active, this may be so because of worry about your partner missing out, rather than because of your own enjoyment. The social myths about sex mean that you may not talk to anyone else about this lack of sex, including your partner, and this can feel very isolating. Despite the fact that not all couples are sexually active and that these difficulties are very common in pain, you may feel that you are the only person

who is struggling with this. Keeping quiet about it may mean that you don't realise that in fact your experiences are very normal.

Building up gradually

When sex becomes painful, you tend to avoid it when you can, only approaching it when you feel that you 'should' or when your partner wants to be intimate. This leads to an 'all-or-nothing' pattern of sexual activity, for example having no sexual contact for a couple of months and then having penetrative sex followed by a severe flare-up of pain. This 'all or nothing' pattern doesn't usually work well for someone with persistent pain. A more helpful approach is to have regular sexual contact, which doesn't necessarily involve penetrative sex. As well as helping your body get used to sexual activity in a way which does not trigger a flare-up, it reduces your anxiety and helps you to stay intimate with your partner rather than avoiding any physical contact. There is a well-established graded approach to building up sexual contact known as 'sensate focus' which works well in reducing your anxiety as well as minimising the risk of flare-ups. This 'step-by-step' approach involves taking your sexual relationship back to a level where you feel your pain is manageable, staying at this step for a while (for example, a few weeks), and then moving up to the next level.

Desensitisation

Many persistent pain conditions have elements of 'hypersensitivity'. That means that sensations which should normally be pleasant and normal, such as touch and stretch, can feel painful. We now have studies explaining that this can be because of changes in your nervous system and not necessarily because you are causing any harm. The good news is that the nervous system is capable of changing the response and the technique used is called 'desensitisation'. For this technique to be effective, it is important to feel reassured that some temporary increases in pain do not mean that there is any harm. It is possible for a lot of people to gradually build up their tolerance by exploring self-touch regularly. The desensitisation process can be compared to going to a pebbled beach and hurting the first time you run across the beach but gradually, as you do it more frequently, the soles of your feet get used to it – they 'desensitise'. Once confidence grows in self-touch, a partner can be involved as long as there is clear communication about what, how long and where touch, stretch and intimacy can be tolerated. For this purpose, Sensate Focus techniques can be useful as a step-by-step approach to introducing intimacy without the pressure of achieving full penetrative intercourse.

Medication side-effects

Medications for pain are sometimes associated with unwanted side effects that can affect sexual desire and performance. Should this be a concern, you can discuss this with your GP or pain specialist. Sometimes people use medication to manage temporary increases in their usual persistent pain; often known as 'breakthrough' medication. It can be useful to take breakthrough medication prior to sexual activity if a flare-up of pain is likely afterwards. It can be very helpful to develop non-medical strategies for these flare-ups, and if you do take medication you must take it as prescribed.

Communication

Like with any activity involving someone else, you need to communicate to get what works best for both people. This can feel difficult whether you are in an established relationship or with a new partner. It can feel particularly difficult if you 'buy into' the myth that sex should always be spontaneous and so you should never need to discuss it. To help with communicating about sex, you may want to rehearse what you are going to say, and in the case of a new partner, when you are going to say it. Emphasising how much you want to be close to them, and that you want to avoid your pain getting in the way of this, will reassure your partner that you are not using your pain as an 'excuse' to avoid sex. If it feels difficult to talk, you could consider showing your partner this leaflet to read, as a starting point for a conversation. It is difficult to communicate about what you would like without knowing it yourself, so you may want to start the desensitisation or sensate focus steps described above by yourself, so that you know what you can do without triggering a severe flare-up of pain. You can then involve your partner at a later stage.

Prioritising sex

Like any activity which you want to do regularly, you need to prioritise sexual activity in order for it to become a normal and an enjoyable part of your life. It is very easy for it to get 'lost' in all the other pressures of day-to-day life, whether you have persistent pain or not. You also need to prioritise the elements of your romantic relationship which will help you to stay close, such as being affectionate and spending time together. Sometimes these elements of a relationship can suffer when sex is difficult, as there is a worry that any physical affection will 'lead to' sex, which will be painful. Communicating about this so that you can continue to be affectionate often makes a big difference to how close you feel to a partner.

Before sex

Remember that pain can be 'wound' up by several factors including activity, mood, environment and biological changes. Some of these factors may be possible to change and some not. Through self-management approaches for pain, you can manage aspects of life that can wind up the pain, which can help when engaging in activities which are important to you, including intimacy. There may be strategies you can use to manage the pain prior to intimacy; particular those that help you feel relaxed. You may wish to involve your partner in these strategies such as having a bath or shower together, having a massage or listening to relaxing music.

Managing flare-ups

Flare-ups of pain are a normal part of living with persistent pain, and if they happen after sex it is best to have a plan for how to manage them, as this reduces your anxiety about them. Ideally you also communicate this to your partner so that they understand what you are doing. A flare-up plan for pain may involve, for example, having a hot bath, taking pain medication, using an ice pack, doing some stretches, and reminding yourself that the flare-up will pass.

Self-help resources:

- Relate: www.relate.org.uk - for online resources and couples counselling, including counselling around sexual relationship difficulties
- Overcoming Sexual Problems – Vicki Ford, 2010 – self-help book on cognitive-behavioural therapy for sexual difficulties (not just pain-related),including details on the sensate focus approach

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