

ARE WE SPEAKING THE SAME LANGUAGE?

By David Nunns FRCOG

Frequently doctors and patients do not speak the same language when it comes to pain. As a doctor, I might ask a patient 'How is your pain today?' and expect to hear one of three options from a patient: 'the same', 'better' or 'worse'. Obviously, we hope for an improvement in pain and diligently write this in the notes. A worsening of pain might trigger a different prescription to hopefully achieve option one for the next visit.

Rarely, however, in chronic pain is this type of outcome so simple. Ask a patient what she misses in life as a consequence of chronic pain or ask how the pain impacts on her general lifestyle and you get a much more personal picture of the pain rather than the previous three options. For example, 'I missed that wedding because I wasn't able to travel in the car for three hours'; 'I can't walk the dog anymore'; 'I've had to take time off work and it's meant financially we are worse off". These sorts of responses give us a real idea of how pain can influence the woman, her family and her social circumstances. The truth of the matter is that doctors and patients often do not speak the same 'pain language'. It is difficult with general practitioners and hospital doctors, as consultation times are so short. Often the doctors are different on each clinic visit and there can be little understanding of the nature of your problem. Appointment times can be quite spaced out, or there can be absence of communication between you and the doctor. Many patients are left in limbo. It can often seem that the whole system is against you and your pain.

Getting the most out of the consultation

In chronic pain a dependent doctor-patient relationship has been at the heart of care for many years. Recently there has been a challenge to this medically-led approach to a chronic problem which has many aspects to it. Clearly you need your doctor to help diagnose the reason for the pain to exclude any serious underlying disease and start medical treatment. It involves engaging with your health professional, who may be a GP or hospital doctor and it can be difficult: trying to find parking for half an hour, waiting in the waiting room for an hour, or being nervous and anxious about seeing the hospital consultant or GP, can make many women walk out of a consultation none the wiser.

There are many options, however, for trying to overcome this: take a friend, write your questions down before the consultation, or even ask your GP if it is possible to have a double appointment slot for the consultation. It is quite OK to ask your doctor for a copy of the letter that he or she sends to your GP and this just helps. At least everyone knows that they are speaking the same language and there is no confusion. One frustration many patients with chronic pain have is disjointed care and an absence of a plan. A plan or a time frame is quite helpful in chronic pain. When giving a prescription for a new treatment make sure you have clear instruction on how to take the tablets or treatment, and be aware of any potential side-effects. Often patients simply do not give treatments enough time to work and this is frequently a fault of the health professionals, because we simply fail to remind patients that side-effects do happen. If you can get a follow-up appointment or even contact details should a treatment not work that can also be very helpful and reassuring.



Turning the volume down

Chronic pain can be a way of life for many people and there are many ways of turning the volume of this pain down that involve not only medical treatments but lifestyle changes. Much of the current medical approach to chronic pain is based on drugs taken by mouth: these can include simple painkillers such as paracetamol, anti-inflammatory tablets and codeine type preparations. These are often safe to take and very helpful in pain when taken regularly or even just with flare-ups. There are many drugs prescribed specifically for chronic pain such as the tricyclic antidepressants and the anticonvulsants, i.e. gabapentin and Lyrica. These drugs are taken on a continual basis, often on an increasing dosage, to help reprogramme the nerves and turn that pain sensation down; they do not often work completely but can reduce the intensity of the day-to-day pain. A good way of recording the effectiveness of a treatment is to keep a pain diary. This is a daily score using a visual analogue scale. Imagine a line 10 cm long. 0 is at one end, 10 is at the other, score 10 is the worse pain ever and 0 out of 10 is no pain. You should record your pain on a day-to-day basis along this line, and it gives you an idea of how your pain may be improving or even not responding to treatment. As a general rule, pain scoring more than 5 out of 10 is considered as 'moderate'.

Shift from doctor to patient

As mentioned above, the medical model does not always work because there can be a heavy reliance on medical treatments such as drugs to help the pain and symptoms. There is increasing emphasis now amongst chronic pain experts to shift the emphasis from the doctor to the patient, i.e. patient-centred care. Chronic pain has many different facets to it; the level of pain you experience on a day-to-day basis can be influenced by many different factors. Factors contributing to the pain experience include: stress, anxiety, side-effects of the treatment, failure to respond to the treatment, tiredness, work and social losses and flare-ups of pain.

Becoming engaged with your own care is a crucial step towards helping turn down the volume of pain that you are experiencing. Engaging in your treatment and taking an interest in your problem is extremely helpful rather than depending on the medical model, where often it is at crisis point that individuals can end up calling out emergency GPs or even end up in casualty departments. Education is crucial and there are a number of self-help educational resources available to you on the VPS website. Many women find educating themselves opens up new treatment possibilities and also helps them take existing medical treatments in a more effective way. For some, with education and understanding comes acceptance and a discovery of how to live with the problem and help deal with day-to-day pain in a more effective way, cope with flare-ups and begin to have a more fulfilling life.

1 Coping with physical symptoms

Many of the drugs that are used in chronic pain have side-effects, and understanding of these side-effects and a realisation that when starting a new drug side-effects do subside often helps. Taking drugs at night can help with sleep and can sometimes avoid morning tiredness. Constipation associated with some of the side-effects may be alleviated by taking a regular laxative. Having painkillers at home for flare-ups when taken regularly might also be another option. These are examples of how drugs can be used to help with specific physical symptoms. Stress and anxiety can lead to



heightened physical pain and your perception of pain is higher when stressed. There are many ways of helping to overcome stress and anxiety: breathing exercises, relaxation, massage, quietness can all help.

2 Changing unhelpful behaviour

Chronic pain can affect your mood or your general lifestyle. Pain often leads to inactivity, a lack of general exercise and even over-compensatory eating and drinking alcohol. These obviously have knock-on effects on general fitness, weight gain and body image. Many patients with chronic pain do benefit from an acknowledgment and change in the lifestyle they lead through a combination of pacing, setting goals, getting fitter and becoming more active.

Pacing is a valuable skill used in helping manage chronic pain, and enables an individual to plan and monitor daily activity levels and have some control over the consequences of pain in their activity. Sometimes with chronic pain it is easy not only to do too little but in some people too much physical activity, an over-compensation mechanism, can lead to more pain. This 'boom-bust' approach to physical activity can often lead to flare-ups of pain: it is not the best way to control the pain. Pacing is an established technique in the management of chronic pain by using a slow but progressive series of activity and exercises without using pain as a marker of whether too much exercise has been done.

Goal setting as well can be very useful: planning a trip, doing a cruise can give an individual a sense of focus and direction.

Getting fitter and becoming more active has many advantages as listed below:

Improve muscle bulk, strength and flexibility
Reduce joint stiffness
Control weight and improve body and flexibility
Improve balance and co-ordination
Reduce fatigue
Sleep and stamina improve
Lift of mood, self-esteem and confidence
Release body's endorphins
Help manage setbacks and flare-ups
Improve sex life

3



Managing moods and unhelpful thinking

Chronic pain, particularly vulvodynia, has an impact on not only the individual but also the partner and the family. Anxiety, depression, guilt and frustration are all common emotions felt with chronic pain. Isolation is a big factor as well, as the vulva in society today still remains a difficult area to talk about with friends and family. Isolation should ideally be overcome in this problem, as a problem shared is a problem halved, and many patients find just sharing the effects of vulvodynia on them, with a friend, family or even a member of a support group can be extremely helpful. Contacting a self-help group or contacts through the VPS website are certainly an option if you have nobody to turn to.

Managing difficult life situations

Finally, the impact of chronic pain on an individual's life circumstances, e.g. finances, housing or work, can have important knock-on effects as a consequence of chronic pain. These are not easy to deal with but are even harder in isolation, and as mentioned above, you should try to discuss these problems with family and friends.

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