

When we consider that one expert has likened the pain of arachnoiditis to that of terminal cancer (but without the release of death), it is obvious we are dealing with a condition that causes extreme pain and thus a massive amount of distress. One correspondent once told me that relief of pain was

“well worth almost anything. (kind of like selling your soul to the devil for any relief)”.

How then are we to describe our pain experience in such a way as to make others realise the extent of our suffering?

The majority of pain sufferers speak of one major problem: not being believed. This tends to relate primarily to medical personnel (and organizations such as benefits agencies) but may also involve family and friends. This sense of not being believed can lead to a terrible feeling of isolation, and may engender desperate attempts to get the message across.

There are numerous ‘assessment tools’ used by medical personnel to help them in understanding the effect pain is having upon the patient. Some of these questionnaires are highly detailed, to the point where they may seem intrusive. A few deal not only with the physical sensations experienced but also the emotional consequences of pain.

Unfortunately, sometimes the results of these questionnaires have been used to suggest that the pain has a psychological component and this seems to the patients to be undermining their credibility and bypassing the pain as a real, physical phenomenon.

However, used correctly, questionnaires such as the McGill can really help to get a true picture of how the pain is interfering with everyday life in all its aspects.

Questions such as

“How much has your pain changed the amount of satisfaction or enjoyment you get from taking part in work/social and recreational activities?”

can be very helpful in establishing the damage being done to you as a person by the pain you are experiencing.

“How much has your pain changed your relationship with your spouse, family or significant other?”

Recognises the strain that unrelieved pain can have upon relationships (we shall be looking at this shortly).

The full McGill questionnaire also includes several questions about mood and ability to cope with stressful situations.

Both the full and short McGill questionnaires contain sections on what the pain feels like.

These include not only descriptive terms such as throbbing, shooting, sharp, burning etc., but also more emotional terms such as frightening, punishing, wretched, unbearable.

There are two main reasons why we need to be aware of the way in which we customarily describe our pain.

Firstly, in consideration of the effect it has upon others to whom we are describing the pain: not only doctors (who may react in certain ways the more emotional we get) but more importantly, family and friends.

Using emotive terms is bound to affect the way in which they react to our experience and may impact upon our relationship with them.

Most family members, for instance, will find it far more distressing to be told about pain that is 'unbearable' rather than pain that is 'cramping' or 'shooting'.

Their reaction will vary according to their individual way of dealing with distressing situations: some will retreat and ignore the complaints; some will rush about desperately trying to reduce the suffering.

Secondly, and perhaps more importantly, the way in which we tend habitually to think of our pain colours our ability to cope with it and the emotional impact it has upon us. As Marcus Aurelius said,

"Your mind will be like its habitual thoughts: for the soul is dyed with the colour of its thoughts."

If we are accustomed to thinking of our pain in emotional terms, then it is likely to have a far greater emotional impact upon us than if we stick to more neutral terms.

We shall be looking at this later in more detail.

One rather unpleasant term for this is 'pain catastrophising', which simply means thinking in highly negative, emotional terms about the pain and its effects, thereby enhancing the negative impact pain has upon our lives.

It is a widely used term amongst psychologists who work with chronically ill patients. It is accepted that catastrophising is associated with a lowered pain threshold and tolerance and with a higher pain intensity and distress.

"When pain and anguish wring the brow",

as Sir Walter Scott wrote, there is a tendency for us to think the worst is going to happen.

According to researcher Dr. David Sheffield([\[1\]](#)), from the Staffordshire University, there is a gender difference: women are more likely to catastrophise.

This may be due to various reasons, because men and women are different in the way they are affected by pain, due to hormonal and metabolic differences (which affect the way medication works) as well as psychological.

(Note that women seem to have less endorphins, the body's natural morphine, than men and kappa opioid drugs work better for women whilst mu opioids work best for men).

This may account for why women appear to be more affected by pain and to become more anxious over what is likely to happen.

However, women do seem to be better at dealing with long-term pain than men.

This may have something to do with society's expectations of how men and women respond to adversity.

"Men have a relatively small repertoire of coping mechanisms. If the 'true grit' approach to pain doesn't work, then they are less good at coping with pain. Women have more strategies and styles and are more likely to enlist friends and other types of social support to help them,"

Dr Sheffield suggests.

There is also some degree of ethnic variability in reaction to pain.

A study in Manchester's Northwick Park Hospital by McAuley, DeSouza et al. ([\[2\]](#)), found that there are differences between British and Indian patients with chronic low back pain.

The nature of the distress caused by pain differs across ethnic groups with depression and somatic anxiety (anxiety with physical symptoms) strongly associated with disability for Indians whereas depression alone for British patients.

Indian and British patients also differ in their beliefs associated with their disability, Indian patients being less likely to believe that they are responsible for the management of their condition whereas British patients are more likely to report the use of passive coping strategies (leaving progress up to the doctor rather than being proactive in their own management).

Below is a table in which there are examples of emotive terms and neutral terms (obviously not corresponding directly to each other).

| EMOTIVE TERM |
|--------------|
| NEUTRAL TERM |

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|---------------------|
| Punishing/agonising |
| Throbbing/pulsing |

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|-------------------|
| Cruel/ vicious |
| Stabbing/shooting |

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| Unbearable/killing |
| Intense/continuous |

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|-------------------|
| Dreadful/wretched |
| Cramping/pressing |

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|----------------------|
| Annoying/troublesome |
|----------------------|

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|-----------------|
| Burning/searing |
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|----------------------|
| Frightful/terrifying |
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|--------------|
| Aching/heavy |
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|---------------------|
| Torturing/sickening |
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|-------------|
| Sore/tender |
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We can see that the emotive terms all suggest a component of the pain other than the actual physical sensation involved whereas the neutral terms concentrate upon the sensation itself.

The latter tend to help the sufferer to divorce the sensation of pain from the emotional reaction to it. We know that nerve-related pain such as that experienced in arachnoiditis can be hard to keep at bay, and this may mean that we need to develop strategies by which we can minimise the emotional impact (and hence our suffering) it has even if the intensity of the sensation itself is not eradicated.

Interestingly, a study published in late 2001 ([\[3\]](#)) found that functional MRI scanning (fMRI) shows differences in blood flow in certain parts of the brain according to differences in beliefs about pain control.

A questionnaire called the Beliefs in Pain Control Questionnaire (BPCQ) designed by a Professor of Health Psychology, looks at patients' beliefs about where control of their pain lies, whether within themselves (Internal), with doctors (Powerful Doctors) or is down merely to chance (Chance).

The study found that patients with fibromyalgia varied in their brain's response to painful stimulus according to their belief about the source (locus) of their pain control.

Whilst at this stage, the complexities of pain processing remain poorly understood, there does

seem to be a correlation between patients' beliefs and their processing of pain.

This means that we must consider closely what exactly those belief and ideas might be and concentrate on maximising the beneficial ways of thinking whilst minimising the unhelpful ones.

In addition to various forms of pain questionnaire, there are a number of different assessment tools that you might be asked to look at.

These include the Oswestry Low Back Pain Disability Questionnaire, which has 10 parts, concerned with pain intensity, personal care, activities such as walking, sitting etc.; sleeping, sex life, social life and travelling.

The SF-36 is a short 36-question assessment instrument, which affords a standardised assessment of patients' health status. It contains 8 separate indices of health and functional limitations both physical and emotional, social function, mental health, pain, and vitality. However, this may not be particularly useful in patients with chronic low back pain.

As regards questionnaires more specifically aimed at picking up psychological problems, tools such as the Beck Depression Inventory and the Zung Self-rating Depression Scale may be useful.

There are, in fact, quite a considerable number of specific questionnaires that have been developed by various specialists throughout the world, which relate to different aspects of chronic pain.

Whilst it is unlikely you will be asked to fill any of these in, their titles are interesting and suggest some areas that we need to consider. Of course, you will notice some familiar concepts:

- Fear of Pain Questionnaire (McNeil, DW, Rainwater, AJ)

- Coping with Health Injuries and problems (Endler, N, Parker, J, Summerfeldt, L)
 - Anxiety screening questionnaire (Wittchen, HU, Boyer, P)
 - Multidimensional locus of pain control (Terkuile, MM, Linssen, A, Spinhoven, P)
 - Pain Anxiety Symptoms Scale (McCracken, LM, Zayfert, C, Gross, RT)
 - The Pain Beliefs Questionnaire (Edwards, LC, Pearce, SA, Turnerstokes, L)
 - The Pain Catastrophizing Scale (Sullivan et al)
 - The Pain Beliefs and Perceptions (Williams, DA et al)
 - Tampa Scale for Kinesiophobia
 - Coping Strategy Questionnaire
 - Hospital Anxiety and Depression Scale
 - General Health Questionnaire
 - CSD 90
 - Middlesex Hospital Questionnaire
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[1] Sheffield D, Biles PL, Oram H, Maixner W, & Sheps DS Psychosom Med, 2000; 62, 517-523 Race and sex differences in cutaneous pain perception.

[2] <http://www.brunel.ac.uk/research/crr/barcelona.html> McAuley JH , De Souza LH , Main CJ ,Frank AO, Sharma V Ethnicity and the Psychological Characteristics of Chronic Low Back Pain Disability.

[3] Farrell et al, ImmuneSupport.com Supraspinal Activity Associated with Painful Pressure in Fibromyalgia is Associated with Beliefs about Locus of Pain Control

