

I believe that suffering is the sum of pain and other physical symptoms and a number of psychological factors, including emotional reaction to those symptoms. Fear, anger, grief can all make the pain worse.

Very often, the ability for the doctors to completely remove the pain is limited, so the aspect we need to work on is the emotional reaction.

That is NOT to say it is a matter of "will power" or "strength of character" which implies that "failure to cope" equals lack of "moral fibre."

It is not helpful for professionals to claim to empathise with the patient (this is where the support groups are helpful), nor to imply criticism of a patient for what the doctor may perceive as "abnormal illness behaviour"(AIB): after all, the vast majority of doctors have not experienced the despair of facing a life in uncontrollable pain.

In any case, I have yet to be convinced that there has been a viable definition of "normal illness behaviour," which must surely render the AIB term meaningless.

Besides which, it is utterly preposterous to use a blanket term for all illness when each condition, let alone each patient, brings with it such a variety of presentations, and of course, the so-called "text-book case" of even the most straightforward of conditions may well prove to be the exception rather than the rule.

I believe the best approach is to help you to realise any unhelpful coping mechanisms you may have: this still places the onus for change upon you (which is inevitably necessary) but avoids doctors using the pejorative terms "abnormal",, "poor coping skills",, "psychogenic" etc. (especially bearing in mind that this may influence other clinicians when they see you in future).

Clinicians must recognise that arachnoiditis causes a wide variety of symptoms, which, at first glance, might appear unrelated to a spinal condition, but do, in fact, have a valid clinical basis.

You, as the patient, may well appear to describe a rather exhaustive catalogue of symptoms and be overstating your case.

In reality, it is likely that you are struggling to make sense of a bewildering array of persistent pains, bizarre sensations etc., for which you have already been told there is no medical explanation: but alongside the symptoms, there exists an equally persistent fear that your condition is either deteriorating or there is some undiscovered serious, perhaps fatal illness.

Certainly, it is well recognised that centralised neuropathic pain is a form of torture and indeed, one eminent specialist has described the pain of arachnoiditis as being like the pain of cancer, without the relief of death.

It is absolutely essential for us as individuals and our family to be assisted in decentralising our illness; that is, to remove the illness from the centre stage, with everything else in life revolving around it.

We need skilled help in assigning it to the sidelines so that the focus of the life, not only of ourselves, but also that of the entire family, is shifted from the continually draining negativity of arachnoiditis to more positive matters, be they ever so small and seemingly insignificant.

So often when yet another attempt to be more positive or to exercise is followed by a "flare-up", it is tempting for us to throw the baby out with the bath water and give up.

An all-or-nothing approach is pretty much inevitably doomed to failure. We need to recognise that usually we will go through the one step forward, 3 back, 2 steps forward, 1 back, 4 steps forward, 3 back etc. etc. We may even need to come to terms with a gradual decline in our condition.

Whilst the idea that arachnoiditis is a progressive condition remains a contentious one, it does seem that some people do not stay on a plateau like the majority: they may get worse, usually gradually, but in a few cases, often after a relatively minor accident such as a fall in the street, there may be quite a rapid decline.

In any case, it is quite clear that no one can give an individual arachnoiditis patient an accurate prognosis and what lies ahead for us remains an unknown.

This uncertainty is, of course, itself a source of fear and depression, but looked at another way, having to take life a day at a time frees us of the need to worry about tomorrow and we can shed a pointless worry that can drain our mental and emotional resources.

That is not to say that we should not make any plans for the future, just that we need to adopt an attitude of flexibility, a touch of 'che sera, sera' (what will be, will be). This is trite, but nevertheless true.

Some of the techniques that may help include:

Cognitive therapy: using thought processes to gain control over the pain and negative emotions: guided imagery (either visualising body parts and imagining a healing process or it can be day dreaming yourself into a lovely scene in your head), relabelling (denoting the pain as 'just another sensation, thereby removing the emotional component), recognising negative thoughts (countering them with positive ones), distraction (taking your mind off the pain) etc.

Meditation: techniques such as 'focused intentional stillness'; learning to quiet all thought by placing attention on breathing in and out regularly and/or repeating a mantra: a short positive saying that encourages you to feel calm and at peace mentally.

There are many different techniques, and they don't require sitting in a particular position for a long time. You can meditate anywhere, walking, or in the bath, for instance.

Developing your own personal mantra can also be helpful in getting you through stressful situations, as you can mentally repeat it to yourself to induce a feeling of calm and confidence in being able to cope.

Yoga is a discipline which combines awareness of bodily functions, mental and emotional state and also spirituality (in fact the name means 'yoke' or 'union' in Sanskrit, the ancient language of India, the aim of yoga being to unite mind, body and spirit).

It can be quite therapeutic, laying particular emphasis on breathing, body awareness and relaxation (which is why it is included here rather than in the exercise part of the article: in order to stress the mental approach of yoga, as it is often viewed with trepidation by many people who think it involves complex and painful positions such as the lotus!).

There are a number of different types, which vary in their approach. Meditation is combined with the asanas, or posture exercises, which are just one of 8 stages of physical and mental training designed to achieve union.

Pranayama or breathing exercises helps to balance the muscular and skeletal systems and can act at a deeper level to harmonise all the internal organs.

Kundalini yoga aims to awaken latent energy situated (like a 'coiled serpent') at the base of the spine, whereas Hatha yoga emphasises asanas and pranayama and Raja yoga emphasises meditation.

Hypnotherapy: thought to be helpful to combat central pain.

Self-hypnosis: using meditative techniques, it may be possible for you to relax into a hypnotic trance, which is essentially similar to deep relaxation. Regulation of heart rate, breathing and perception of pain can be controlled during the 20 minutes or so that the auto-hypnotic state is maintained.

Autogenic training: this relaxation type therapy enables the patient to become aware of every part of his/her body and allow each part in turn to feel heavy and then relaxed. Progressive muscular relaxation (PMR) is a similar technique.

Counselling: individual: general issues: losses; specific issues: sexual, continence etc.;
Couples

Learning new skills: loss of job/mobility may prevent previous skills being used. It is vital to find new interests and hobbies. This can help to displace pain as the central focus of life.

Humour: maintaining a sense of humour may seem like an impossible task, but as it has been said "Laughter is the best medicine."

Music: often a source of comfort, relaxation or a way in which to echo one's inner turmoil; sometimes a source of inspiration.

SPIRITUAL MATTERS: to look at a truly holistic way of treating any condition, one must consider body, mind and spirit. Spirituality is of course an intensely personal matter and cannot be adequately addressed in an article of this nature.

However, suffice it to say that one's spiritual needs must be met, just as our bodily and mental needs are. This might involve 'conventional' religion, Eastern philosophy, or indeed, anything that you, as an individual, find uplifting and supportive.

It is also important to remember that chronic illness can be a tremendous challenge to religious beliefs and often people suffer a crisis of faith. One sufferer I know has likened himself to Job from the Book of Job in the Bible: the man who lost everything!

Other people may be able to turn to religion as a comfort and I know of many people who are sustained by their faith.

