

John Donne wrote about the strength of fear:

“Fear insinuates itself in every action or passion of the mind, and as gas in the body will counterfeit any disease...so fear will counterfeit any disease of the mind...I know not what fear is, nor I know not what it is that I fear now; I fear not the hastening of my death, and yet, I do fear the increase of the disease; I should belie nature if I should deny that I feared this.”

Fear is one of the predominant emotions that run through daily life in those who are chronically ill. In particular, people with arachnoiditis, especially those without an established diagnosis, tend to be subject to fear, because there is little known about the expected prognosis, or the course of the disease.

Therefore the future becomes highly uncertain. One thing is known, that there is no cure at this point in time, but the extent of the pain and loss of function remains unknown.

Fear tends to revolve around the following:

- What does the pain mean? Could there be something more serious going on that the doctors have missed? Is there something I'm not being told? \*
- Does the pain mean that there is ongoing damage?
- Fear of the pain, especially of it escalating out of control
- Fear of loss of function and how that will affect life
- Fear of the effects of the illness on finances and on relationships
- Fear of the future
- Fear of not being able to cope

\* Note that loss of confidence in medical staff is likely to compound this fear. Also, there may be someone we know who had a similar problem, which turned out to be something very serious, or even life threatening like cancer.

Fear may be quietly colouring the background of daily life or may surge up at times in the guise of anxiety, which is associated with many unpleasant symptoms of its own.

Even a low-grade background fear can sap life of pleasure and can influence our attitude to life, to challenges, to our relationships, to the future.

At its worst, fear can be paralysing.

It is not a sign of weakness to feel this fear, but a perfectly understandable emotion bearing in mind the many ways in which life is affected by arachnoiditis.

Dr. Claire Weekes, wrote 'Self Help for Your Nerves' in 1977( [\[1\]](#) ).

It is a compassionate and caring book that aims to show people with 'nerves in a bad way' that the strength to recover is within them. The passage quoted below encompasses some important points that bear remembering:

'The sufferer ...is neither fool nor coward, but often a remarkably brave person who fights... to the best of his ability with commendable although often misdirected courage.

He may fight through almost every waking moment, with sweating hands and tensed muscles, agitatedly trying to force forgetfulness of his desperate state by consciously concentrating on other things.

Or he may pace the floor of his mind, anxiously searching for a way out of his miserable prison, only to meet one closed door after another."

Dr. Weekes maintains that what is happening to the individual results from *fear* and his response of fight or flight, which she terms the "fear-adrenalin-fear cycle".

She suggests that fear is the basic cause of nervous symptoms,

"anxiety, worry and dread being only variants of fear in different guises."

As she points out, many people are loath to admit even to themselves that they are afraid, such is the stigma. Dr. Weekes describes the torments of someone who develops "fear of the very feelings that fear itself had aroused."

Fear of pain itself can be a barrier to effective pain management.

A Dutch group have discussed the notion that chronic pain and chronic fear share important features.

They looked at patients with low back pain who had a substantial fear of movement and/or re-injury and found that with certain behavioural techniques, over a period of time, the patients were encouraged to undertake previously avoided activities and were able to do so.

Professor Crombez, of Gent, Belgium, suggests that pain-related fear creates a hypervigilance to pain.

Crombez notes Waddell's statement that

"Fear of pain and what we do about pain may be more disabling than pain itself" ( [2] )

His research with chronic pain patients

"is focused upon the determinants (pain catastrophizing) and consequences (avoidance, physical deconditioning, hypervigilance, negative affect) of excessive fear of pain."

A number of studies have shown that pain-related fear is one of the most potent factors in limitation of physical function and level of disability in chronic pain. (Asmundson et al., 1999 [3] Vlaeyen and Linton, 2000 [4] ).

Vlaeyen suggested a cognitive-behavioural model of pain-related fear (Vlaeyen et al., 1995 [5] ).

If pain, possibly caused by an injury, is interpreted as threatening ('pain catastrophizing'), pain-related fear can evolve.

Avoidance may become anticipatory rather than in response to pain increase, or may be a part of a rest/overactivity cycle that many pain patients become trapped in.

Periods of over-exertion lead to increased pain, which then leads to stopping most or all activity (complete rest), and a repeated yo-yoing of too much and too little exercise which tends to persist because the increased pain becomes associated with activity, whereas in fact it may well be more to do with deconditioning (loss of muscle strength and stamina through inactivity).

Avoidance may be entirely logical if the patient believes that activity is likely to cause damage. This situation may arise if the medical personnel have given incomplete or contradictory

information.

Fear is thus not due to an irrational belief, but to an erroneous one. Fear based on incorrect beliefs is likely to be dissociated from actual pain experiences.

Pain-related fear leads to muscular reactivity (increased muscle tone, twitching, tendency to cramp and spasm etc.), hypervigilance (increased attention to and awareness of pain sensation), and avoidance behaviours (avoiding the activities that are thought to be triggers for pain).

Long-term avoidance may subsequently increase levels of disability, disuse and depression, through physical deconditioning and emotional demoralisation. Depression may well contribute to the pain experience thus fuel a vicious circle of increasing fear and avoidance.

Asmundsen remarked in a recent paper in the Canadian journal of Pain management( [\[6\]](#) )

"The association between chronic pain and anxiety may not be particularly surprising when one considers that, in the acute phase, both pain and target-oriented anxiety (or fear) motivate actions that serve to minimize the threat and maximize the likelihood of successful escape...."

"It is possible that one causes the other; that is, fear might cause chronic pain or, alternatively, chronic pain might cause fear. It is also possible that each influences the other."

## **SERIOUS CONCERNS:**

1. Persistence of one emotion such as blame or anger

2. Denial
3. Resistance to medical advice to the detriment of health
4. Creating other physical problems (immobility leading to muscle wasting)
5. Low levels of contact with other people
6. Major changes in life e.g. divorce
7. History of anxiety/depression for more than several months
8. Suicidal thoughts and plan
9. Family/friends expressing undue concern.
10. Loss of hope

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[1] Latest publication Thorsons 1995

[2] <http://www.psy.kuleuven.ac.be/leerpsy/crombez.html>

[3] Asmundson GJ, Norton GR. Allardings MD. *Pain* 1997; 69(31): 231-6. Fear and avoidance in dysfunctional chronic back pain patients.

[4] Vlaeyen JW. Pinion SJ. *Pain* 2000; 85(3): 317-332. Fear-avoidance and its consequences in chronic musculoskeletal pain

[5] Vlaeyen JW. Kole-Snijders AM. Boeren RG. van Eek H. *Pain* 1995; 62(3): 363-72. Fear of movement injury in chronic back pain and its relation to behavioral performance.

[6] Asmundsen GJG *Pain Research and Management (Journal of the Canadian Pain Society)* Spring 2002 Vol. 7 No. 1 Anxiety and related factors in chronic pain