

STEPS II

Strategies to Ease Pain Suffering

Hello everyone.

Another year is nearly over and I hope it has been a good one for all of you. No doubt there has been pain, no doubt you've had difficult times, but I hope there has been laughter and fun as well. Because life must go on, despite arachnoiditis. And that means life in all its technicolour complexity.

What does quality of life mean to you? As you may know, I now work in Bath on in-patient Pain Management Programmes. The psychological model here differs from traditional Pain Management in many ways.

The model that underpins the Programmes is complexly different from Cognitive Behavioural Therapy (CBT), which I have written about in the psychological article. CBT is a model based on the theory that our behaviour is driven by how we think. Therefore in order to have 'better' behaviour, we need to change negative thinking into positive thinking. This places the entire emphasis of therapy on changing thoughts and ideas.

All fine and well, and CBT has been an effective therapy in Mental Health and Pain Management for decades. However, there is now evidence that traditional Pain Management does not predict effective outcomes in terms of pain intensity, pain-related distress, physical disability, psychosocial disability etc. These are not just psychology terms: they are about the important aspects of a fulfilled life.

This is a source of lively debate amongst Psychologists. I'm not a Psychologist and so, with apologies to my colleagues, here is my take on the difference between traditional CBT as used in Pain Management, and the Contextual CBT (CCBT) we use here (which I wrote briefly about

recently).

To begin with, I'd like to borrow a metaphor from Lawrence LeShan who wrote a book on Holistic Medicine. He likened traditional doctors to mechanics, whereas holistic practitioners are gardeners. That is because medicine has tended to view the body like an engine.

In fact, the body is much more like a garden, needing careful tending. Similarly, the mind is, I think, something we need to view organically. I think that CBT basically views the mind as an engine. If thoughts are negative, the engine malfunctions and the behaviour is ineffective.

CCBT, on the other hand, recognises the enormous complexity of factors that drive behaviour. Just as healthy plants need various different things to grow well (good air quality, soil quality, the right amount of rain at the right time, the right amount of sunshine) and individual plant species have different needs, so peoples' behaviour is driven by a multitude of factors including their life history, environmental reinforcement etc. etc. Again, each individual has their own needs. A plant planted in the wrong place will not thrive. Similarly, therapy must take into account the context of someone's life: what their life is about.

The trouble is, when we first ask someone that question, "What do you want your life to be about?" we tend to get very blank looks. Healthy folk and chronically ill folk alike, in this day and age, people tend not to look too closely at this sort of question unless there has been some sort of crisis such as a bereavement. Actually, people with chronic illness find this question particularly difficult as so often illness has stripped their life bare and narrowed their horizons so much that they lose sight completely of what was once important to them.

So the first precept of CCBT is to re-acquaint people with how their life has been recently. This can be quite a challenging and painful process. Sometimes it leads to what psychologists call 'creative hopelessness' which means that recognising how awful life has become and how little one is coping can lead to a recognition that 'the only way is up'.

Awareness of effective and ineffective lifestyle strategies is the first step towards acceptance of the reality of life with chronic pain.

A little digression here. I have already written elsewhere about pain and suffering. I feel that pain is the sensation, suffering is all the other 'stuff' that goes with it: emotional reaction (anger, fear, anxiety), behavioural response (avoidance, activity cycling), social consequences (financial problems, relationship difficulties). Hence, note the change of title from STEPS to STEPS II: the original Strategies to Ease Pain AND Suffering has been changed to simply Strategies to Ease Pain Suffering.

Mostly, even with all the might of medical technology, sadly we can do little to alleviate pain. However, Pain Management aims to give people a toolkit to help deal with suffering. To return to the gardening metaphor, this isn't a mechanic's toolkit, it is a gardener's toolkit.

One of the most significant factors in suffering is how much we struggle to control pain. Most people who come on the Pain Management Programmes aren't people who have 'given up', they are more likely to be people who are constantly fighting the pain, and/or trying to ignore it. That takes an enormous amount of effort, which drains them and leaves them less able to carry on. One of the main tasks in CCBT is to develop awareness of how ineffective this struggle is, and that what is really needed is workability and flexibility. Does a particular strategy (such as ignoring pain, pacing dictated by pain level) really work in daily life and can it be adapted to different situations as needed?

The next thing we tackle is fusion: people tend to get stuck on certain ideas ('I can't....') which get in the way of doing important things. Often there is a tendency to be defensive: a strong need to be 'right' and be believed.

CCBT emphasises contact with 'now'. Chronic pain patients may be focussed on either the past or the future and to avoid what is going on right now, usually because 'now' is a painful time and place. That is partly a cultural thing, we are all encouraged to strenuously avoid unpleasant things (if you have a headache, adverts tell us how to get rid of it. Stressed out? You must relax!) But... what if we can't avoid unpleasant experiences?

Incidentally, the International Association for the Study of Pain (IASP), an august body, defines pain as 'an unpleasant sensory and emotional experience' so why would anyone not want to avoid it? Well, the answer is, of course it is entirely normal to want to avoid it. That is where traditional CBT falls down. It asks people to turn negative ideas about pain into positive ones. That, CBT practitioners say, is the way to change their behaviour.

CCBT, on the other hand, says you don't need to change the way you think about pain. You can expect to think negatively about it and to feel you should struggle against it. That's OK, you don't need to feel badly about feeling badly or give yourselves a hard time about not being able to ignore pain. BUT...the big thing is, you **DON'T NEED TO ACT ON YOUR THOUGHTS**.

This is where mindfulness comes in, which is a way of being aware of thoughts and feelings without reacting to them. It is non-judgemental and tries to get away from the 'gritted teeth' strained way people tend to deal with pain and their emotional reaction to it. Mindfulness allows people to notice experiences and simply let them come and go. It is loosely based on Buddhist principles. It is not, however, the same as relaxation or meditation. More on this another time...

CCBT next looks at what the individual values in their life: typically in a number of important domains such as family, individual relationships, work, health, personal growth. Everyone assigns different levels of importance to each domain. Usually, people find there are one or more areas of their life that are sadly lacking and on which they'd like to work. The Programmes incorporate an exercise based on what individuals would want said about them if they had emigrated perhaps and their friends and family were gathered at a party. How would you want to be remembered?

Chronic pain patients have often lost sight of their values. Without understanding what is important to them, it is really difficult to formulate appropriate goals which can be worked towards to live a life that matches the values. Goals that other people want them to do will be meaningless and are often not achieved.

The final and highly important stage of CCBT is committed action based on the goals identified from the values. This is very much about doing not just talking about it. All the rest of the therapy is meaningless if you don't act on it. This is the change in behaviour part of the therapy. This is doing what works in the context of your life, despite pain and despite thoughts and feelings. It is about noticing pain without doing anything about it.

The reason I have written about this now is to encourage you all as you move forward into 2007. No doubt next year will have its fair share of pain and tears, but wouldn't it be great this time next year to look back and say, 'Look what I managed to do, despite my illness!' For me it is all about not being defined by my illness but living my life the way I want to. It's the best way I know of getting one up on arachnoiditis!

Best wishes for a very Merry Christmas and a Happy and fulfilled New Year.

DocSarah.