

"Health and disease are often conceived exclusively as states of the organism, but they represent social definitions as well" John Clausen.

One of the most important points about chronic illness is that it doesn't necessarily equate to a proportionate level of disability.

What is disability?

I would define disability as being 'defined by one's illness': by oneself or others. That isn't, of course, the true definition which runs along the lines of being rendered less able, by limitations of health, be they physical, mental or emotional.

Of course, in these days of political correctness, the terminology should perhaps be '...challenged'. Quite what that would make arachniacs I'm not sure: perhaps 'pain challenged'?

I actually feel this is quite an apposite term for us, because we most certainly are just that: challenged by pain in so many ways.

There are many different types of disability, ranging from 'developmental' (including genetic abnormalities) to 'degenerative' (including conditions such as progressive muscular atrophy, dementia etc.) via traumatic (injury: spinal cord, head injury, amputation etc.)

One can also divide disability into purely physical or mental.

Chronic illnesses don't fit into these categories particularly well. They often encompass a combination, with perhaps a predominance of physical or mental impairment: in multiple sclerosis, for example, there may be mainly physical loss of ability, but it may be accompanied by a loss of mental faculties as well.

Even in conditions that have no recognised organic impact upon the brain, the stress and strain of ongoing illness can have a significant effect on mental and emotional aspects of life, as we have discussed already. This means that not only is there physical disability to cope with, but also the impairment due to the mental and emotional strain.

We must also bear in mind that Arachnoiditis and other conditions involving chronic pain tend to cause invisible disability.

This may be advantageous in that other folk are not forever staring or making just audible remarks, but then again, it can cause no end of problems when people fail to believe that there is anything really wrong.

Whether or not you see yourself as 'disabled' is very much an individual matter. Personally, I have difficulty in equating my limitations with being disabled as such, but I guess it's a question of semantics in a way.

But then again, by my own definition, if I refuse, as I do, to be defined by my illness, then perhaps I really am not disabled.

If we look at psychological aspects of disability, we can see a core of frequent responses. These are only a small representation, because in reality, people's responses are as varied as they and their own disabilities are.

However, I think it is helpful to glance briefly at some of the concepts involved:

First, let's look at some of the unhelpful* approaches:

(*Note: I won't be using pejorative terms such as 'good' and 'bad' because they carry an emotive suggestion that I don't think is useful)

1. Idolizing the norm: '... the normal standards of behavior are rigidly defined and held forth as the single criterion for desirable or even allowable.' (1) This unhealthy response means that we are comparing ourselves with 'normal' people and judging our abilities alongside theirs.

This might well include their coping abilities as well as their physical attributes. It is, however, vital to remember the following quote from Connie Peck's book 'Controlling Chronic Pain':

'You are responding in exactly the same way as any other human being (including your doctor, your spouse or your psychologist) would if given the same set of circumstances.'

2. Redemptive compensation: an attempt to compensate for a perceived inadequacy or inferiority: which may be a form of indemnity, but is essentially destructive and therefore unhelpful.

An example of redemptive compensation is an attempt to be pleasant towards everyone no matter how unlikeable they make themselves, because of a need to be perceived as a 'nice' person despite the illness.

Other examples include pushing oneself too far in unwise activities to compensate for limitations in certain tasks.

3. Physique as prime motivator: this means attributing one's actions or limitations directly to the disability, which places the disability at the heart of one's functionality.

4. Centrality: a perceptual phenomenon in which something becomes central to our perception of a situation; allowing disability to take centre stage permits it too prominent a role in our lives.

5. Contrasts: comparing 'now' with 'then' (troubled present with easier past) or perhaps oneself with someone else. This can be very distressing and debilitating and is sometimes part of an 'if only' mentality; it can be related to a grieving process which we will look at further later.

6. Reductionism: reducing an individual's personality traits, behaviour, beliefs etc. to one particular aspect of their personality or physical status: this minimises the whole person and encompasses what I was referring to as 'being defined by one's illness' as well as the common occurrence of medical professionals making assumptions based upon perhaps a patient's demeanour during brief consultations. Needless to say, this can be very damaging.

7. Negative spread: a similar concept in which a small, isolated trait is enlarged to ascribe negative characteristics to someone or a situation. This might refer to a third person's attitude or indeed to our own, the latter involving 'awfulising' a situation: rendering the difficult impossible, for example. (E.g. 'I can't walk very far, so that means I simply can't go out anywhere';)

8. Secondary gain: an unpleasant little term over-utilised by medical and paramedical personnel. I have discussed this further in Myths, but it does need to be included, because occasionally people are unaware of the way in which their mind may be manipulating them a little: for example: someone might stop going to visit an in-law they don't like but rather than admit the dislike to their spouse (and sometimes even themselves) they genuinely think they are too unwell to go.

One of the difficulties about being ill all the time is the perception that we have to somehow compensate for our 'shortcomings' and be 'nicer': see redemptive compensation. Actually, honesty, especially with oneself, is always the best policy.

9. Succumbing: giving in to the limitations of the disability: the opposite of coping; the dictionary definition is: 1. to yield to superior strength, force or overpowering appeal or desire and 2. To cease to exist, to die. (Webster's dictionary)

Now let's look at the useful concepts:

1. Adaptive compensation: the use of attitude, behaviour, techniques and technology to reduce the impact of disability.
2. Containment: this means containing the effects of disability and refusing to allow them to contaminate or spread to other aspects of life. In other words, limiting the problems.
3. Solution-focussed thinking: trying to focus more on answers than on problems; a shift from victim-based thought to regaining a sense of control.
4. Enlarging the scope of values: finding new interests or re-evaluating current beliefs and values thereby enhancing the value of aspects previously minimised or overlooked: in other words, 'accentuate the positive, eliminate the negative.' as the song goes.
5. Normalisation: I'm not really sure I like this American term too much. What is 'normal' after all? However, the principle behind it seems sound: the aim being to render our lives as much like those of everyone else as possible. 'Conditions of everyday life for people with disabilities...should approximate the norms and patterns of mainstream society as closely as possible' (Wright [1983]) In other words, we shouldn't be forced to be different, or perhaps, more pertinently, to be made to feel different. I suspect this applies more to those with visible disabilities, but perhaps we should adapt the concept to apply to the notion that our lives should not be rendered unrecognisable by our illness: we should still be able to have a quality of life that allows interactions with family, friends and society as a whole. We need therefore to view ourselves as part of society: isolation is a very common problem for folk with chronic illness and I shall be exploring this further later.
6. Positive spread: getting the best out of a situation; obvious really, and I suppose sociologist-speak for counting one's blessings; but perhaps a little more than that, it is about taking positive thinking a step further: seeking out the good in a person, a situation or an object. There may sometimes be little obvious source for positivism, but there are actually very few situations that are unmitigated disasters. I guess a sense of humour is one example of a way in which we can use positive spread; taking a kernel of amusement and expanding it. This may not sound possible given the daily grind of pain and problems we have to endure, but I know of many individuals with arachnoiditis who manage to hold onto their sense of humour.
7. Subordinating the physique: this rather grandiose term is about recognising that physicality, the physique, is not the most important aspect of life and that other aspects are far and away more rewarding to pursue; these might include relationships, interests, spirituality etc.
8. Decentralising: the opposite of centrality: banishing the illness out to the periphery of one's life, thereby allowing more life-enhancing aspects centre stage.
9. Coping: a small word for a huge concept. There is no such thing as the best way to cope: everyone does it differently and we all fall by the wayside sometimes. Intermittently failing to cope is not really a failure, but is in fact, I think, part of the overall coping process itself. The main thing is to have and to sustain a core belief that one CAN cope no matter what the illness throws at one.

So, in summary, I would venture to suggest that disability is as much an attitude as a measure of function. I reiterate my statement that chronic illness is not directly proportional to disability.

A final point: the word INVALID has two meanings:

1. Powerless: unable, disempowered, null and void, obsolete, disabled
2. Weakling/sick person: 'lame dog', 'lame duck', 'softy' (taken from Roget's Thesaurus)

It is not merely a matter of how others regard us that counts, but primarily, how we perceive ourselves: if we believe we are in-valid then our whole attitude is likely to add to our problems.

"There are people out there who don't regard their disabilities as a burden." Ted Kennedy Junior, who lost a leg at age 12)

"Unless you shrug off your affliction as though it were no more than some mildly inconvenient impediment, the standard of physical and moral support you receive goes into dramatically precipitous decline." Gilbert Adair, A Closed Book.

Note: Internet resource:

DisABILITY links available at: <http://www.eskimo.com/~jlubin/disabled/all.htm>
<http://www.disabilitynow.org.uk/>