

## **COPING WITH THE PSYCHOSOCIAL EFFECTS OF CHRONIC ILLNESS**

### **ON INDIVIDUALS AND FAMILIES**

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Diagnosis of chronic disease means many changes that can effect physical and emotional well-being, work, sex and family life. The pressures introduced may lead to changes ranging from the breakdown of the family unit through to bringing it closer together.

Chronic disease can mean a lot of adversities. They can include pain and discomfort, fear and uncertainty about the future, limitations in physical abilities, changes in appearance and lifestyle. A range of emotional effects such as anxiety and depression commonly appear as well.

If left unmanaged/untreated the emotional distress can make a bad situation worse. Quality of life in areas such as work, family relations, leisure and social activities and perhaps interfere with their physical rehabilitation and care.

There is a high prevalence of emotional distress in chronically ill people. Psychologists are interested in preventing or reducing this distress. In particular they are now researching issues like:

- the personal and social ways they cope with the problems and distress brought on by the illness.
- how the person's personality before the onset of illness effects their emotional reactions: in particular whether they were prone to anxiety or depression before. People with such prior histories have a higher risk of strong emotional reactions to chronic illness because it becomes yet another stressful event for them. Their psychological resources may have been drained and left them unprepared to deal with the effects of illness.

- the usefulness of drugs in treating depression in chronic illness.
- the usefulness of non-drug methods of coping with emotional distress such as family support, counselling, specific coping skills training/patient education programs, support groups and relaxation and exercise programs.

Two big potential psychological problems in chronic illness are **anxiety and depression**.

Looking first at anxiety - it can mean worry and uncertainty about one's ability to cope with changes brought by the illness. It tends to be highest in the early stages but not always. It is usually episodic *i.e.* occurs in relatively short-bursts. It can come in waves as new phases of deterioration emerge.

And while anxiety in the chronically ill may be influenced by how anxious a person you were before there are also specific sources of anxiety that many people report especially in the early stages of the illness and its treatment. Common triggers of high anxiety are - waiting for test results, the diagnosis of severely debilitating or life threatening illness and the shock it produces, medical procedures, the side effects of treatment, changes in lifestyle *e.g.* in work-related abilities, dependence on health professionals, and fear of recurrence, complications or worsening of the condition.

Not only the patients but their families can experience this anxiety. For example in cancer patients it peaks for both patients and families at the time of cancer surgery.

In some illnesses the best predictors of subsequent anxiety and depression were the person's first thoughts and feelings about the degree of threat, harm and loss they thought they would experience. Their earliest expectations seem to set the tone of their subsequent anxiety reactions.

As for depression about 1/3 of all hospital inpatients report moderate depression and up to 1/4 suffer from severe depression. Again this can be a function for their prior tendency to depression, (up to 1/2 of depressed cardiac patients may have been anxious or depressed before their illness) the continual stress of the illness or a direct result of neurological/ biological changes of the condition itself. Some say it peaks shortly after the diagnosis and others suggest it is most severe when people realise the full extent of their disability and after going through a number of frustrating experiences.

When you are depressed in the face of chronic illness it can be difficult to sort out what signs and symptoms are attributable to the illness itself *e.g.* the fatigue, loss of energy and motivation, sleeplessness and weight loss *vs.* those that are a psychological reaction and therefore more amenable to psychological techniques. Managing this side of depression is not helped by people who believe that you are supposed to feel depressed after a diagnosis of a chronic illness. This attitude can lead to the depression going untreated.

One guideline to **sort out the physically-based aspects of depression from** the more easily managed and less inevitable **psychologically-based** ones is to assess your self on the following seven items that discriminate abnormally high levels of depression from amongst groups of chronically ill people. (Refer to the Beck Depression Inventory )

1. Sense of failure
2. Loss of social interest
3. Sense of punishment
4. Suicidal thoughts

5. Dissatisfaction

6. Indecision

7. Crying

Other **factors that may influence likelihood** of depression are:

(i) Family and personal history of depressive episodes.

(ii) Whether or not your self esteem was heavily weighted on physical achievement or your body image.

(iii) The severity of the disease - the more severe it is the more likely is depression. When the condition produces significant physical impairment, depressions lasting more than one year are more common.

(iv) Pain and disability in conjunction with a lower age.

(v) Lack of social support. The condition itself can create fear and aversion in family and friends. They may avoid the person physically; avoid open communication; show forced cheerfulness; or minimise its impact. When under extreme stress the way the distress may be expressed (*e.g.* anger that others don't seem to care) can drive supports away and compound depression.

(vi) Meaningfulness of life rated lower (fewer reasons for living.)

(vii) Over-protectiveness by caregivers (being 'wrapped up in cotton-wool.')

Unlike anxiety, which tends to come in cycles and tends to be short-lived, depression can be a long-term reaction to chronic illness. For many illnesses it can last a year or more *e.g.* breast cancer, stroke, heart attacks. In one study 2/3 of a group of diabetics suffered recurring major depression over a 5 year period. This depression was not related to the severity or any complications of the disease. The depressed patients had worse glucose control than other diabetics.

However, in chronic low back pain depression often presents differently. Technically the usual diagnosis of depression requires that its symptoms be present for two weeks continuously. Clinicians experienced with this group of patients commonly notice troughs that are briefer than a fortnight. And so the depression is often ‘atypical’ - not like the more continuous depression seen in other patients.

Depression can affect your mental status over time - you may see declines in your concentration, memory and your ability to reason and to put things in perspective: a major asset when it comes to managing stress.

The point of this emphasis on the emotional reactions to chronic illness is to alert you to the common high risk of emotional distress associated with chronic illness. *If you know what the traps are you're more likely to avoid them or minimise their effects. You are less likely to be uncontrollably or unconsciously drawn into the pits of worry and despair. You can then care for yourself better and focus your energies on managing those aspects of your condition that you can control.*

Seek outside help for this. Or pull together your own inner resources and social supports to solve the practical and emotional problems of chronic illness.

**What can you do to cope better** given this awareness of the problems for you and your family?

1. Communicate your concerns and queries to your doctor, specialist or other health workers. If necessary rehearse or write out the questions you may have before an appointment. Shop around if they don't listen sensitively but remember they can't read your mind. You have to let them know what you want.
2. Check out the advisability of using anti-depressants since they hold promise in managing major depression in chronic illness. Take the drugs as prescribed. Using medication inappropriately can at best be useless or at worst heighten the chances of unpleasant side effects. Be prepared to have the dosage altered to find an optimal level for you.
3. Seek out a good counsellor or family therapist when crises occur. Often just a few sessions can help solve immediate problems.
4. Check out patient education programs and support groups; get information about your condition when you are emotionally able to absorb it: share your concerns with others; find out how they solve practical problems, make plans and organise their lives and how they personally cope and keep meaning in their lives.
5. Learn some relaxation and stress management techniques. Physical relaxation techniques such as a slow, steady 6 second breathing cycle can reduce the effects of anxiety and nausea from chemotherapy and decrease pain. Mental stress management techniques that help you take a different perspective on your stresses and other techniques that give you some rest and time out from prolonged strain may make a big difference.

**Three commonly reported strategies** used by people who “keep their heads above water” in the face of chronic illness are:

(i) Distancing - trying to detach themselves from their stressful situation (*e.g.* “I didn’t let it get to me. I refused to think about it too much.”)

(ii) Positive focus efforts to find meaning in the experience by focusing on personal growth (*e.g.* “I came out of the experience better than I went in.”) In one study of cancer patients 90% found at least some beneficial changes in their lives as a result of their illness. They often reported an increased ability to appreciate each day and were inspired to do things now instead of postponing them. They generally put more effort into their relationships and felt that they were more aware of others feelings, had more sympathy and compassion toward the unfortunate. They report feeling stronger and more self assured.

(iii) Seek out social support (*e.g.* “I talked to someone to find out more about the situation.”) Social support from family and a number of friends and organisations is a very important resource in coping with the chronic disease. When this is high, people live longer, adjust more positively to their illness, have better health habits (*e.g.* sticking to medical routines) and use health services more. The nature of the disease can adversely effect potential support resources (*e.g.* reaction of family and friends to cancer, epilepsy and AIDS.) Being in a state of extreme stress and expressing it in a manner that drives them away can also reduce this social support when it may be most needed.

The best kind of **social support** is that which is flexible enough to meet the person’s various needs. Three **main areas of benefit** people report are:

(i) practical assistance with things like housework, transport to medical appointments and having errands done when the person is unable to manage.

(ii) Emotional support. At times this may be more valuable and is usually considered most important when it comes from others the person is close to.

(iii) Information and advice. Most people prefer that this comes from experts and say it can be a problem when friends and family give too much of this. Social support groups/self-help groups can be a major source of support especially when the members are good role models for coping efforts over the long-term. Unfortunately they tend to appeal to well-educated, white middle class females. Their potential has yet to be more widely spread through the community.

**Warning signs that you may be having trouble coping** or “in danger of drowning” might be:

(i) Lots of 'escape fantasies' or wishful/magical thinking (*e.g.* “I wish that the situation would go away.”)

(ii) Efforts to avoid - the stress by overeating, over-drinking, excessive smoking, overuse of medication.

(iii) Lots of self-blame, helplessness or angry expression of emotion (blaming others) instead of a more constructive attitude like “It's not my fault that this has happened to me. Factors outside my control lead to this illness but I do have a responsibility to help in my rehabilitation and care as challenging as that will be. I can exert some control over the effects of this illness.”

(iv) Passive acceptance (*vs.* actively adjusting your lifestyle to make the best of the situation), forgetting the illness, fatalistic views of illness, withdrawal from others.

(v) Rigid, long-term denial of the illness and its effects. Denial though can be a good coping mechanism at certain times in the adjustment to chronic illness. *e.g.* in the early stage high deniers tend to adjust better in the long run to some illnesses - it acts as a kind of shock absorber and protects you from facing

too much too soon. Some research is beginning to suggest that people who make the best adjustment "try to change the things they can and accept the things they can't." *i.e.* to use problem-solving on aspects of the illness that are amenable to change and to use emotion-focused coping techniques for aspects that can't be controlled. They can move back and forth through coping strategies rather than stick to a predominant coping style.

**What characterises families, as opposed to individuals, that cope better** with the illness of an adult family member? Many families can handle illness without any major disruption. One researcher labels this group as 'energised families'. They are characterised by:

- (i) Variety and frequency of interactions within the family e.g. visits from extended family members.
- (ii) Established community ties e.g. church affiliations.
- (iii) Encouragement of independence or autonomy of various family members. A member is allowed to be a separate individual as well as part of the family unit.
- (iv) Creative problem solving using the family skills and unique talents of the individuals who make up the family.
- (v) Ability to adjust to role changes within the family e.g. the traditional roles of the mother as manager of the household and father as breadwinner may be shared by other members or one other member.

Some of the **factors that may work against family cohesiveness** in this time of adversity could include:

- (i) The reverse of these e.g. inflexibility, inability to re-organise with respect to changing roles.
  
- (ii) Changing cultural expectations e.g. parents are freer from the obligation of financial support once the children finish school and move into the workforce than they were 100 years ago. Not surprisingly though, the other side of the coin is that children are no longer expected to assist in the support of their parents when they are aged, ill and no longer independent. What the children should do is less clearly defined than it was a few generations ago.
  
- (iii) Where the family members do not see the long term consequences of the disability e.g. in the earlier more vague/ambiguous stages of the illness, or when the symptoms fluctuate. Once the diagnosis is clear and accepted other family members can often re-organise and family bonds become less disrupted.

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