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### **Living with a Chronic Disease**

There are few people in the world that haven't been sick at some time in their life. Fortunately, on most occasions, these unpleasant periods are of short duration and it isn't long before one is back into life's routines. During the 'sick period', a person is cared for by loved ones, visited by friends, and encouraged to get well quickly. Generally, the person looks sick and has a disorder known to most people. They even have a rough idea of when they will be well again. Though unpleasant, this kind of 'being sick' is bearable to both the individual and those around them, particularly in view of the fact that an end to their illness is in sight.

For those who suffer from a chronic disorder and particularly one relatively unknown to the general public, but obvious to them, being ill is a different situation altogether. A painful disorder that drags on and on, tests the mettle of the sufferer and the patience and tolerance of those around. In relation to such a disorder, members of the public, at their best, are both curious and cautious, while at their worst, cruel and discriminating. Such attitudes are more than enough reason for sufferers of disorders such as scleroderma/lupus to educate themselves and the public, learn to deal with intolerance and ignorance, and most of all, learn to survive at the highest possible quality of life. To be ill is not simply to be in a biologically altered state, but also to be in a psychologically and socially altered state. While there may be some preoccupation with physical symptoms, it is important to consider the way in which one copes psychologically.

Generally speaking, three major problems face a person suffering some form of chronic and publicly observable disorder. Firstly, there is the inevitable question 'why me?' and all the emotions that go with such a question: anger, frustration, sadness, bitterness etc, all of which are perfectly normal reactions to an abnormal and unpleasant situation. Providing one has a good 'emotional shoulder' to lean on from time to time, and 'let it all out', little other attention will be necessary. If there isn't someone to talk to, sufferers need to contact a qualified counsellor and make an appointment. If there are feelings of being 'super stressed', and talking with your support person is insufficient, it may be necessary to make an appointment to see someone professionally qualified. The local doctor is best placed to advise on locating an appropriate person.

The second big problem to be faced in relation to a chronic relapsing disorder is 'what does this mean for my life?' Inevitably, immediate and long-term changes are necessary if one is going to make the most of life, given the way the disorder affects individuals. This will mean frustration and perhaps loss and grieving as one lets go of favoured activities no longer possible. It will also mean that loved ones and close associates will also need to make changes, not the least of which is reducing their expectations based on their awareness of past performance. There will need to be a focus on 'what I can do' rather than 'what I can't do', and even a time perhaps to learn new skills and activities. A person with a broken leg is not a broken leg but a person with a broken leg. Remember, a sufferer is not a 'case of scleroderma/ lupus', but a person with scleroderma/lupus, and that there are many other aspects to life.

The third problem, having struggled with the 'why me'? And 'what does it mean'? is the reconstruction of one's life taking into account the challenges and limitations of the disorder. For this, both professional help and the support of family and fellow sufferers is imperative.

To make the most of one's lot when suffering a chronic debilitating condition, four bases need to be covered. First, there needs to be time out for pleasurable activities; second, there needs to be time for a primary relationship (spouse, friend, parent etc); third, make time to belong to a supportive group; and homebase - a need to get professional help in good time. While each of these points deserves expansion the message is plain and simple, in making the most of your

life. There is an important need to educate oneself and those around you about the condition to enable others to provide support through the low spots and encouragement for

the victories. Surviving at the highest possible level doesn't necessarily take people with super ability, but people able to bounce back, and everyone can do that with a little help from their friends.

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