

Conclusion

In this book I have given an overview of the illness known once as epidemic neuromyesthenia and today as Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, and other names I may not have heard of. It is still quite a mystery disease to most doctors; probably those most knowledgeable about M.E. are the sufferers themselves. There is more to learn about it every day, and it is important that M.E. people communicate with each other about things that help, and continue to support research and the education of non-believers. It is hard to believe this in 1991, but people afflicted by Multiple Sclerosis had to battle for years to have their illness accepted as being genuine. Many of them were regarded as malingerers or neurotics 20 or so years ago.

Perhaps one day there will be a 'treatment' for M.E., some medicine to take, some magic bullet to make it all better. Predictably, the main focus of current medical research into treatment is looking at ways of destroying the virus, or of regulating the confusion it causes the immune system. This is fine, so long as the basic principles of helping the self-healing process are also applied - rest, good food, fresh air and light, freedom from stress, and spiritual well-being.

In this book you will have noticed there is a word that is hardly used - that is the word *cure*. Perhaps you are disappointed, having hoped to find guidance to lead you to the magic remedy that will make you fit and full of energy to live the life you used to enjoy. Of course there are quite a number of M.E. people who get so much better that they consider themselves cured.

However, the possibility of relapse is always there, and it is really foolish for someone who seems to have recovered to push his or her body to the limits, or to go without sleep, or eat badly. The viruses that trigger off M.E. are still around, either having gone back to sleep (becoming latent) in your body, or still floating around in the community.

It is useful for anyone who has a chronic illness to consider the two terms 'health' and 'fitness', because they can be erroneously thought to be the same thing.

What is meant by being 'fit'? This is a state that is desired by athletes, and by people who want to be able to exert themselves without suffering ill effects. One's heart, lungs and muscles must be in perfect working order. Fitness is, however, a purely physical condition, and ignores the state of the mind and the soul. Someone can be apparently superbly fit for the task of running up mountains or having the endurance to run 25 miles, yet develop a prolonged illness following a viral infection. The most common cause of death among joggers seems to be heart attack.

Health, on the other hand, has a much more subtle meaning. I understand it to mean being integrated, balanced in oneself, at peace with the world, and content. A state of 'perfect health' - if it exists! - would mean the perfect functioning of body and mind, and a pure spirit. In M.E. the body does not function properly, certainly, but I do believe that there is more to health and life than a super-fit (or even half-fit) body.

I know two quite different people:

Mr Super-fit takes great care of his body; he runs or plays squash every day, and goes skiing or rock-climbing (both to top levels of endurance) at weekends and holidays. In his forties, he has the body of someone much younger. However, he is unhappy, tense, gets lots of headaches and vague symptoms, is antisocial, irritable and sometimes depressed.

Mr Laid-back is also in his forties. He is a bit overweight, as he enjoys his food and wine. He loves his job of teaching young children, loves entertaining friends, is generous and always cheerful. Apart from walking and standing all day at school, and pottering in the garden, he takes no exercise whatsoever, and does not feel the need for it. He has not had a cold or a day off work for years, and has no bodily complaints.

Which of these men is healthiest? And which of them would cope best with getting M.E.?

As stated earlier on, health means 'wholeness'. The M.E.-stricken body may not be whole - sometimes it seems as though every part of it is broken down. But continually I am amazed at the wholeness of the spirit and personality of people I come across who are physically disabled in some way.

I can still recall vividly a patient I knew in a cancer and chemotherapy unit. She was only 38, her family were still young; she had an incurable cancer, was wasted and in a lot of pain. She had plenty to be resentful about, and to be scared of. Yet, following some sessions of healing with her parish priest, and knowing that many people were praying for her, she announced one day that she was healed. Her body did not miraculously rid itself of the cancer overnight; to a casual observer she still seemed desperately ill. What had changed was that she had accepted her condition, stopped being afraid, and felt completely at peace with her family, friends and her Maker. In her last few weeks of life she gave out so much love to those around her, that those of us caring for her felt enriched by her company. In one sense this lady *was* healed, and healthy.

So I think that one of the keys to getting on with M.E. is *acceptance* of how you are. This is not the same as wallowing in self-pity and saying, 'I'll never be any better,' No, it means saying:

M.E. has come into my life, it is a fact of life. I shall do what I can to improve the way I feel. I shall change my lifestyle, feed my body well, nourish my immune system, and give myself lots of tender loving care. I shall stop yearning for what I cannot have for the present, and count what blessings I have. If I listen to my body and look after myself I shall probably get quite a lot better in time. If I do not get back to how I used to be, I will nevertheless continue to be alive and able to appreciate many good things in life, by living from day to day and looking for joy in little things.

Those who cope best with M.E. seem to be the people who try to go along with it, who adapt to living with M.E., rather than fighting it. Ironically, there are other illnesses that one fights to get the better of - there is the saying 'fighting for life' against a severe infection or after an accident perhaps. But with M.E. one needs to be a bit less aggressive about the illness. There is a need for fortitude and resolution, certainly, and some discipline about not doing things. Because nobody who has M.E. ever knows exactly when he or she is going to get better, it is very important to be able to get on with some sort of life, even if it only 10 per cent of the amount of living there was before.

So, if it takes one week to complete a task, such as writing a letter, that used to take 20 minutes, never mind. The work done will have no less value!

Living with an illness such as M.E. is possible at all levels of affliction. Remember it does not kill, and that the majority do get somewhat better.

Whether or not you have any religious faith, you can appreciate that this prayer is one for M.E. people to learn and use:

*God, grant me the serenity
to accept the things I cannot change,
Courage to change the things I can,
and the wisdom to know the difference.*