Chapter 6

Plan of Management

As you probably know, you cannot go to your doctor and come away with a prescription for a drug which will cure M.E. Take comfort from knowing that most M.E. sufferers get somewhat better in time. There is strong evidence to show that those who rest early in the illness have a better chance of recovery.

Present estimates are that if you have a diagnosis of M.E. and you have been ill for less than a year, you will have about a 70 per cent chance of recovery within 5 years. Of course this means that 30 per cent will still have M.E. after 5 years. However this is an illness which usually has ups and downs, and if you can learn to manage your life with M.E. then you are unlikely to stay at your worst all the time. It is natural to remember only the worst times, the days when you feel absolutely awful, but think also of the days when there has been an improvement in energy, and the feeling that life may still be good.

There are three broad categories that describe the course of the illness:

1. Those who gradually get better, then stay better.
2. Those who have remissions and relapses (the remissions may last for several years), but never seem to shake the disease off permanently.
3. A small number of unfortunate people in whom there is no remission, and who remain ill for years.

Keeping a Diary

I have found it helpful, when going through a bad time, to refer back to a good day and to imagine myself in that happier state again. For this reason I think that keeping some sort of diary is useful. Much has been said about the value of writing down all the bad symptoms as they occur, and what you have eaten, drunk, and done - especially looking at exercise. In this way you may see a pattern developing that shows what things cause a relapse in you.

But it is just as important to commit to the diary the *good* days, the experiences that have given you pleasure or made you laugh, anything that has caused an improvement. As most M.E. sufferers have poor memories, a diary can be useful to refer to before going to see your doctor, and to look at the results of any therapies you have tried. It is best to try to develop a routine of scribbling something every morning or evening. Even a weekly diary is useful.

However, there are some people for whom the idea of monitoring their illness suggests that they might be a hypochondriac. This is understandable: the British in particular do not think it is 'quite the done thing' to take too much interest in one's aches and pains. But if you take an interest in the good times as well as the bad, then optimism may balance the hypochondriasis.

Another good reason for keeping a record over a period of months is that it is hard to remember exactly how you were six months ago, and while there may be ups and downs the general trend is more likely to be one of very gradual improvement, which will only become obvious when you refer back to the diary. The decision to keep a diary is an individual one. If you are too ill to write, perhaps your carer can keep some sort of a record for you.

Helping Yourself

What has happened in a person with M.E. is a lessening of the body's defence system which deals with viral infection.

Factors Known to Decrease the Immune System Function

Virus infections can cause a reduction in numbers and function of lymphocytes.

Stress - especially if protracted. This includes physical stress caused by, for example, exposure to cold or exhaustion, and mental or emotional stress such as is caused by bereavement, overworry, divorce.

Nutritional deficiencies

Refined carbohydrates – i.e. glucose, sucrose and, fructose - reduce available vitamin C and impair white cell function.

Certain drugs - such as steroids, anticancer drugs, the contraceptive pill, possibly some antibiotics (by upsetting the natural balance of friendly bacteria in the body), and immunosuppressants used after transplants.

Exposure to chemicals - including smoking, which depletes the body of vitamin C.

Recent research has shown a definite link between psychological stress and immune functioning *(Lancet,* June 1987). What seems to be relevant is not the amount of stress one is exposed to, but how one handles it; thus someone who remains depressed for a long time after a bereavement or serious family illness has a greater chance of becoming ill him- or herself. So the observation by many M.E. sufferers that they thought they had undue stress for a period before developing M.E. is logical. If severe stress had led to their immune system not working so efficiently, then their bodies would not be able to deal with a viral infection properly.

The aim of any plan of management should be to encourage the body to mobilise its own healing forces. We have an amazing capacity for healing and repair of damage in our bodies; unfortunately, for all sorts of reasons this healing force is often suppressed, as explained above. Anything that will allow the immune system to become stronger and to overcome the persistence of viruses in our cells, should be valuable for an M.E. sufferer.

A person with M.E. has little energy. Therefore it is vital that none is wasted on unnecessary activity. This includes physical activity, worry and anxiety, and the energy required for digesting the wrong foods, and for getting rid of chemicals or drugs.

If the immune system is having to deal with other foreign agents, or allergic reactions, it will not have enough resources to deal effectively with a continuing viral infection.

Your state of health results from the balance between things that decrease your healing energy, and those things that promote recovery.

Negative Factors

Too much exercise
Lack of sleep
Worry
Mental strain
Work stress
Sadness, bereavement
Loneliness
Cold and damp
Hunger
Wrong food
Sudden shocks
Surgery
Most drugs
Anaesthetics
Infections
Poisons (alcohol, chemicals, smoking, pollution, etc.)

Positive Factors

Physical rest
Sleep
Freedom from anxiety
Mental rest
Relaxation
Calmness
Love and friendship
Warmth
Joy, laughter
Good, nourishing food
Fresh air and sunshine
Lack of chemical pollution
Avoiding infection
Patience and optimism

If you look at these lists, you can see that all the positive factors are the sort of things we try to give our children and those we love. When you are ill, you need to spoil yourself a bit, to give yourself those good and natural things you would wish for a loved one. It is unrealistic to expect others to provide them all, though if you have love and support from others it is a tremendous help; but you ***can*** organise quite a lot of positive forces for yourself.

In planning a campaign for living with M.E., it is best to do it in stages, and have an order of priority. There is not yet enough evidence that the following suggestions will be helpful in every case, however reducing exertion and resting seem to be essential for all sufferers. Other lines of management have ***all helped some people***. The advice offered is not aimed at achieving a total cure, but rather to lessen the severity, encourage more remissions, and help you to live more comfortably with the condition.

It is not much use spending money and time on various treatments and at the same time continuing to live on an 'overdraft of energy' so ***rest*** is the first thing to organize.

Things to Do to Help You Cope with M.E.

- Organize your lifestyle to allow for more rest
- Stop unnecessary exercise
- Learn to relax - e.g. meditation
- Accept your limitations
- Improve your nutrition, avoid low blood-sugar levels
- Keep warm at all times
- Take nutritional supplements, especially vitamin C
- Avoid chemical pollution
- Deal with Candida infection if present
- Treat any allergies
- Get more fresh air and daylight
- Learn to handle depression, with treatment if necessary
- Develop positive thinking and serenity (of course this is difficult on bad days!)
- Do not be shy about asking for help
- Apply for things to make life easier (social services, walking aids, etc.)
- Contact other sufferers for support if you feel isolated, such as joining a local M.E. group
- Do not compare yourself with other people who have your illness; some will be more ill, some less, they all have ups and downs like you.

In learning to live with M.E., half the battle is won if you can accept that you just *cannot* live at the same pace as you did before you became ill. To do this you need to realise that your worth is not measured by achievements in terms of being busy, earning money, athleticism or even being particularly good at anything.

Remember, you will probably improve.

The following chapters will talk about these things in more detail.

Of all these suggestions, ***physical and mental rest*** and ***good nutrition*** are the most important.