

## Chapter 8

### Exercise

How I wish that something as simple as gradually increased daily exercise could cure M.E. Exercise is an emotive word in M.E. circles, and the advice generally given by experienced M.E. people is: *don't do it*.

However, a lot may depend on what one means by exercise. At one extreme there is punishing exercise such as running and squash, in which a fit person pushes him- or herself to the limits of endurance and uses anaerobic metabolism. There is no evidence that jogging prolongs life, while it certainly wears out joints and running shoes. Heart attacks do happen to apparently fit young-to-middle-aged people during squash or running sprees (including the American man, Jim Fixx, who popularized jogging!). *Doing vigorous exercise while recovering from any viral infection can be dangerous*, as the heart muscle may be affected by any virus. I do not recollect any centenarian interviewed on radio or TV, when asked 'to what do you attribute your long life', ever mentioning jogging - more usually a gentle lifestyle, with a daily trip to the local pub!

The other extreme is the exercise involved in getting out of bed and putting on clothes, which may cause exhaustion in someone acutely ill with M.E. What may be more relevant is movement and activity, rather than exertional exercise. Suitable exercise for anyone convalescing from chronic illness includes walking, gentle swimming, yoga - and singing.

Why singing? It uses the muscles of the chest, throat and diaphragm. It is creative, expressive, increases oxygen intake and improves circulation; it is good for the spirit; if done with others as a group activity it is fun and sociable. If you sing while sitting, you do not use your leg muscles, which when affected limit nearly all activities that involve walking and standing. You may be surprised at my including singing as exercise, but it is an alternative to painting, writing poetry or making baskets, when more strenuous activities have to be abandoned. You don't even have to purchase the musical instrument.

Every town, and many villages, have amateur choirs and church choirs, which welcome enthusiasm as much as talent. Making music transcends all the differences in age, income, social class and state of health that may exist among participants. There have been times in the last two years when a weekly trip out to sing, even when unwell, has kept me sane. No one minds that I bring cushions and sit all the time.

### Graduated Exercise and Cognitive Therapy

An alternative explanation of long-term disability in chronic fatigue syndromes has been developed by some British psychiatrists (Butler et al./ 1991):

Looking specifically at CFS, it is plausible that an initial infective trigger may begin a cycle in which attributional and cognitive factors fuel avoidant behaviour. The initial symptoms, in particular fatigue and myalgia, engender a state of 'learned helplessness' . . . and may trigger or

exacerbate the mood disorder that is found in many patients. Avoidant behaviour sustains symptoms, by decreasing activity tolerance and increasing sensitivity to any stimulation, as does associated mood disorder. Re-exposure to activity causes more symptoms and more fear. The result is a vicious circle of symptoms, avoidance, fatigue, demoralization and depression, and the clinical picture of CFS.

This theory about M.E./CFS does not accord with the experience of most M.E. sufferers.

The treatment proposed by this group of doctors therefore consists of:

- a) Treatment of depression (if present) with antidepressants
- b) Gradual planned increase in activities that the patient feels comfortable with, including exercise
- c) Cognitive therapy to help the patient break the association between activity and symptoms. 'If I feel ill today, it is because I did too much yesterday' (the logic learned from bitter experience by chronic M.E. patients) is changed to 'If I feel ill today, it is because I have been too inactive yesterday'!

A treatment trial of cognitive therapy and graded activity was carried out in a group of sufferers from chronic fatigue (Butler, 1990). Some of these conditions were self-diagnosed, some diagnosed as CFS by specialists and the average length of illness was five years. 50 people were offered treatment: 32 accepted, and 27 completed the course, which lasted 4-6 weeks. The results were:

23 out of 27 who completed treatment felt better

Of those who fulfilled the criteria for suffering major depression, and who took a course of Prothiaden (a tricyclic antidepressant), 60 per cent improved.

There was an association between lack of improvement/worsening and patients who believed that their symptoms were due to physical disease, as well as those who had positive VP1 (enterovirus in blood). Could I suggest that these 'treatment-resistant' patients actually had M.E. proper?

The overall result was that 74 per cent felt improved after 4-6 weeks. After a further three months, however, this figure had dropped to 65 per cent. It would be interesting to see how many of these people had a *sustained* improvement after a year at the increased level of activity, and how many had relapsed on exposure to a further viral infection, or other stress.

This approach to treatment does appear to benefit some people with chronic fatigue. However, I do wonder how many of those who accepted the treatment had M.E., how many fulfilled criteria for chronic fatigue syndrome, and how many had fatigue from untreated depression or other causes. I find it significant that having a positive VPI test made a subject less likely to improve with this treatment. Probably those people had a persistent enteroviral infection, causing the 'therapy-resistant' disorder in their muscle metabolism.

Before I ever heard of 'cognitive behaviour therapy', I believed that one simple way to differentiate between someone with chronic fatigue due to psychological causes, and someone with muscle fatigue caused by M.E., was an exercise test such as the following:

### *The Bull-in-a-Field Test*

Place the subject in a field. Introduce a fierce bull into the field, and shut the gate behind him. The subject provokes the bull (using a cruelty-free scientifically tested stimulus, of course). The activity and symptoms of the subject are monitored for 24 hours.

The subject with 'neurosis fatigue' will be seen to run briskly across the field, and get over the gate; the next day he will feel less depressed, as a result of the surge of adrenaline and endorphins associated with the hard exercise.

The subject with M.E. fatigue will be seen to walk or stagger or maybe run (if his condition is not too advanced) across the field and collapse by the gate; if alive and not mauled by the bull the next day his symptoms of muscle exhaustion and pain will be much worse, he will complain of feeling ill and 'fluey, and he may be depressed and weeping.

This test has not yet been accepted for authentic medical diagnosis, nor scientifically tested!

Of course, the unnecessary avoidance of *all* exercise, and continuing prolonged bed rest beyond the initial acute stage of M.E. and other post-viral fatigue conditions, can lead to problems such as deconditioning of the heart lungs and muscles, psychological problems, and maybe a belief that one is becoming a permanent invalid. Total lack of use does lead to muscle weakness and muscle wasting. Lying flat for too long causes poor blood pressure control when getting up, and therefore dizziness. Initial attempts of exercise after a period of bed rest will probably result in weakness, unsteadiness and muscle aching in unused muscles.

But too much exercise for an individual M.E. patient leads to symptoms of relapse. So what is the best middle course for someone with M.E. to follow?

Dr D. Ho-Yen, consultant microbiologist at Inverness who has studied a large number of post-viral fatigue patients, has pointed out that there are various sub groups of patients. Which sub-group they fall into may affect how quickly they recover, and how they respond to exercise (Ho-Yen 1990). It is evident when looking at any form of management of this illness, that each patient must be assessed individually; what helps one may be useless for another.

There is no doubt that complete rest in the first week~ or months of a post-viral illness is helpful. Pushing oneself to exhaustion while convalescing from *any* infection delays recovery, and may lead to chronic disability if it is an enteroviral infection. It is during the chronic stage that a *gentle* increase of daily activity may be advisable.

Dr Ho-Yen has written:

Patients' experiences do not show that avoidance of exercise is maladaptive. It is proposed that the recently ill often try to exercise to fitness, whereas the chronically ill have learned to avoid exercise. Recovery is more likely to be achieved if patients learn about their illness and do not exhaust their available energy.

*Available energy* is the key to planning how much to do. As you (hopefully) gradually improve, you will slowly increase your bank balance of energy. It takes a long time, and one day of over-optimistic exertion may push your energy balance back into overdraft for weeks.

One of the things that told me clearly that I was ill before I had even heard of M.E., was my *changed* response to any exercise. Previously, if I felt tired and low in spirits, I used to go for a brisk walk, or dig the garden say at weekends after a busy working week. This exercise would always cheer me up, give me a good night's sleep and refresh me for the next week. After developing M.E I found that even the most gentle exercise would completely shatter me, and led to my feeling ill, hurting all over and crying for no reason. This dramatic alteration in the response to what is considered healthy exercise, is the most classic symptom of M.E., and should distinguish it from other fatigue syndromes.

Another thing not sufficiently appreciated by many doctors, is the difference between the fatigue felt by a normal person after a game of tennis or a 12-mile walk and that felt by someone with M.E. after minor exercise. The former is described as 'healthy tiredness: refreshes the mind, improves the appetite and leads to a good night's sleep. The muscles may ache, but are relieved by a hot bath and sleep. This sort of healthy post-exercise fatigue is known to be good for many cases of depression, and is aptly described in Rudyard Kipling's 'How the Camel got his Hump' (one of his *Just So* stories).

But the post-exercise fatigue typical of *M.E.* is *quite different*, and needs to be experienced to be understood - it is not just tiredness, it is feeling horribly ill, collapsed as though poisoned, with visible muscle twitchings, intense pains in the muscles and maybe in the joints; nausea, sweating, insomnia and nightmares; maybe an elevated temperature and recurring sore throat and tender, enlarged glands. This fatigue (an understatement) is not relieved by a good night's sleep.

### **How Much Exercise is Safe?**

After trying out some new activity or exercise, see if the activity produces a gentle, healthy tiredness, or if it leads to M.E. fatigue. However, even if mild tiredness is produced, the patient needs to be very cautious and slow about increasing the activity. Unfortunately there is no easy predictor of whether an activity is going to harm you.

As an illustration - with apologies for using anecdotal evidence - a few months ago I had a bad experience with physiotherapy, prescribed to help treat arthritis in my hands. I managed two sessions of trying to comply with the physiotherapist's instructions - pulling on a coiled spring of 30 lb tension, to 'improve my upper arm strength'. I am still baffled by the logic of this exercise. The day after the second session, my body rebelled and went into a M.E. relapse that lasted over a week, with all the symptoms mentioned above.

When well enough, I went back and tried to explain that weight-training made me ill, and asked for gentle hand movements. But I was told by the expert physiotherapist that 'we all know now that M.E. is psychological; what *you* need is to stop lying around, and do more exercise: I was astounded by this ignorance, and hurt; I had spent the previous hour struggling to do Christmas shopping in preparation for two guests over the holiday. I caution all M.E. *patients against physiotherapy unless the therapist understands the nature of M.E. muscle function.*

Feeling too ill to argue with her, I decided not to expose myself to further stress, so did not go back. However, I did find that *very gentle swimming* in a local, heated pool, was acceptable to my body, provided I did not exceed four slow lengths, and did not go on days when my muscles hurt.

Unfortunately, there is usually no warning bell to tell you when you have done enough, whether you are swimming, walking, gardening, or doing yoga. By the time you start to feel tired or your leg hurt, you have exceeded the safe limit. The only thing to do is to try something; if it proves to be harmful, rest until recovered, then try it again but *only do half as much*. Learn to read your body carefully to distinguish between symptoms of healthy tiredness, and those that threaten a relapse. Another important way to achieve more activity is to stick to a daily schedule of rest and activities, and then to vary the activities during the day so as not to exhaust different muscle groups, or your brain.

For example, if during one day you aim to do a total of two hours' paper work, plus half an hour of gentle walking (maybe an ambitious day for some people), plus four hours of bed rest, it will work out better if these activities are split up and rotated - such as 10 minutes walk, one hour rest, ½ hour paperwork, etc. Much more is achieved this way. Some M.E. people manage to return to a job by negotiating staggered hours of work with rest during the day.

There seems to be a difference in response to exercise among M.E. patients in the early stages of the illness or in relapse, and among those in relative remission who may be able to cope with exercise better than when they were first ill. I do realise that much of this chapter may be useless for severely affected chronic M.E. people; I am aware of their plight.

You will find that *your body is the best judge* of how much, how often and what type of exercise to do. If you have features of fever, muscle twitchings, spasms, and muscle weakness, your body is telling you its muscles need rest. After a period of rest (not necessarily total bed rest), if the muscles stop complaining and you feel less ill, you may be able to start some gentle daily exercise. If you get some warning symptoms back after the experimental exercise, it was probably too much. The secret is to stop before you start to feel tired.

If you gradually increase the amount you can do and get away with, you may reach a limit beyond which you just cannot go, without a relapse - no matter how motivated you are. This limit must be determined by you and *your body*, not by a well-meaning physiotherapist, psychiatrist, or friend. The limit will vary; it may be quite high during a period of remission, but may be drastically reduced following some adverse factor, such as catching a cold, exposure to chemicals, or physical or emotional stress.

## The Heart and Exercise Capacity in M.E.

There are cardiac abnormalities in the acute phase of most viral infections, which largely disappear after six weeks. A study of heart function, at rest and with exercise, in CFS was carried out by Canadian researchers (Montague, 1989):

On graded exercise testing, 20 of 32 healthy subjects achieved target heart rates, compared to only 4 of 31 patients ... Patients with CFS have normal resting cardiac function, but markedly shortened exercise capacity, slow acceleration of heart rate, and fatigue of exercising muscles long before peak rate is achieved. The data are compatible with latent viral effects on cardiac pacemaker cells, or their autonomic control, and skeletal muscle tissues.

The authors noted that the patients were strongly motivated to exercise, and to gain further insight into their symptoms.

Belfast doctors (Riley, 1990) investigated aerobic work capacity in patients with CFS. 13 patients were compared with 13 healthy controls and with 7 people with irritable bowel syndrome. The CFS group had a reduced exercise capacity, a lower peak oxygen consumption, higher heart rate at submaximal levels of exertion, and higher blood lactic acid levels during final stages of exertion. There were normal carbon dioxide end tidal concentrations, meaning the CFS group did not hyperventilate. The authors concluded that reduced exercise capacity could be due to unfitness, but similar findings occur with muscle damage.

These two studies demonstrate that differing results produce conflicting opinions about causes of poor exercise and heart function in M.E. and CFS people. It would be interesting to repeat these studies on people with proven enterovirus-caused M.E. (as opposed to more generalised chronic fatigue syndrome.)

As stated in Chapter 3, there seems to be involvement of the heart in about 30 per cent of the cases of enteroviral M.E. In a letter 'Myalgic encephalomyelitis: post-viral fatigue and the heart: Dr N.R. Grist (1989) described myocarditis in mice infected by Coxsackie virus, and the similar mechanisms in Coxsackie myocarditis and cardiomyopathy in humans:

It seems likely that similar immunological and metabolic mechanisms in M.E. may also result from chronic infection, providing the organic basis of the post-viral fatigue syndrome ... a condition with severe fatigability and recuperation through rest. The heart muscle does not rest, except terminally. Does 'post-viral dilated cardiomyopathy' \* represent the result of post-viral fatigue syndrome of the unresting heart?

The point of quoting these medical writings is to remind you that too much, or the wrong sort of, exercise could damage the heart in a proportion of people with M.E. Any symptoms of chest pains, shortness of breath, or palpitations that occur during any exercise should be reported to your doctor, and investigated.

However, do not be too frightened by this; the risk of heart attack is far greater for joggers without M.E., than for M.E. people taking gentle, sensible exercise!

\*This is a serious, uncommon condition, a rare complication of Coxsackie infection, diagnosed as a separate entity from M.E.

## Yoga

Yoga is beneficial for circulation and breathing, and seems to improve blood flow to the extremities and hence oxygenation of tissues.

However, yoga is only suitable for M.E. sufferers who are recovering, and the inverted postures which place strain on the neck must be avoided, as must any posture which needs prolonged muscle tension to be maintained. Your yoga teacher should be told you have M.E., and you should not push yourself in any way. The most useful aspect of yoga, the breathing and calmness, can be carried on at home, sat in a chair, and can be learned from a teach-yourself book.

## T'ai Chi

T'ai Chi is a very ancient, gentle, martial art, performed as a series of traditional movements that are intended to unite body and mind. It was developed many centuries ago, and is widely practised in China, Japan, and other countries round the world, for health, meditation, and enjoyment.

You may be surprised to read that a martial art is described in a self-help book for M.E. sufferers! But the movements in T'ai Chi are very gentle and flowing, more like dance; no force or sudden muscular effort is used at all. It can be learned by people of any age, weak or strong. Each muscle is very gently changing between use and relaxation; there is improvement of muscle tone, of circulation of the blood and lymphatics, there is gentle movement of all joints, and the slow turning of the body massages internal organs. It is good for maintaining muscle tone. There is calming of mind and body, and deep regular breathing.

There is on record that a T'ai Chi master, a Mr Liang, learned the art in middle age, after many operations and prolonged illness. He not only confounded doctors who had predicted his imminent death, but was still practising it at the age of 77.

There will be M.E. patients who are not well enough to learn T'ai Chi, because it is performed standing up, taking slow steps and moving the arms. It is recommended for people who are getting better or who are in remission, especially those whose muscle weakness or pain is not so severe. Once learned, T'ai Chi can be performed at home as well as in a class. Even doing a few movements for a few minutes between spells of lying down can be beneficial.

To summarise what has been said in these last two chapters, the *Self-Care Manual for patients with CFS* (Lappmed and Cheney, Feb. 1991) advises (and this includes M.E., although their advice about exercise and cycling may not be appropriate to all chronic sufferers):

'Rest is best' . . . most patients report that rest is the best therapy. You must restructure your life so that it is possible to stop what you are doing when your body says 'stop'.

Most patients report that restructuring their life is the most difficult task, but is ultimately a rewarding lesson that many enjoy sharing with others.

Adjust your daily schedule to accommodate your body rhythm. Follow a fixed schedule of retiring and arising at the same time each day.

Each day you are given a finite amount of daily energy. An inner sense of trial and error will tell you how much energy you have each day, and when you must stop.

You will feel your best by pushing almost to the limit of your daily energy allowance. At the least get up, bathe and dress each morning. Don't regularly exceed your daily energy allowance or you will risk relapse.

Laying down and resting during the day can earn you extra energy towards your daily limit; mental stress and emotional strain sap energy and lower your daily energy allowance.

Save your energy for important things. Hire others to do housework. Get a cordless telephone.

Daily exercise of some kind is essential to prevent deconditioning. On the other hand, never exercise so much as to exceed your daily energy limit or risk relapse. If able, embark on a gentle walking programme. Begin with just a minute or two each day, then try five, then seven, and so on. You may be able to try swimming or cycling later . . . progress gradually. Some exercise each day may actually give you more energy for the next day. *The trick is in knowing the limit of what is therapeutic as compared with what is harmful.*

### **Suggested Further Reading**

Or Darrel Ho-Yen, *Better Recovery from Viral Illness* (Dodona Books, The Old Schoolhouse, Kirkhill, Inverness IVJ 7TE, 1987).