

Chapter 7

Rest and Sleep

A person with M.E. is like a car battery that cannot hold its charge. The battery can be connected to charging leads overnight, and in the morning it appears to be full of energy, but after very little use the lights go dim, the engine won't turn over, and the only solution is to recharge it. Rest is all about recharging your battery.

The metabolic machinery in a M.E. sufferer has gone wrong. Energy is taken into the body via food, and oxygen from the air, but the transformation of these substances into useful energy is inefficient. The power station in each cell (called mitochondria) has a spanner in the works in the shape of a piece of virus protein. The cells which most obviously show up this defect are those of the muscle and brain.

When you use muscles, a by-product of the energy reaction is lactic acid, a build up of which causes pain. This pain and stiffness normally goes away in a day or two in a healthy person. But the M.E.-affected muscle accumulates lactic acid after relatively little work, and also takes far longer to get rid of it and recover.

If you start to feel exhausted, mentally or physically, there is little point in pushing yourself on, as the stage of complete collapse will soon arrive. Many sufferers find out by experience that more can be achieved in a day by doing only a little at a time, and having frequent rests, than by pushing on to the limit and then having to have a long rest. The problem in managing exercise and rest is that by the time you feel exhausted, you may have passed the stage at which a short rest will recharge you, and it may take several days of rest to recover. If you stop before this point, recovery may only take a few hours.

Establishing a Routine

A daily routine, in which you can do things in a rhythm of activity and rest, worked out to suit *you*, is recommended. During a period of severe illness or relapse your daily activity may be merely several trips to the bathroom and perhaps a short time spent in a chair by the window.

It is helpful to think of your available energy as resembling your available cash - as a bank balance. Lots of rest builds up your bank balance of energy. Each morning you will have a certain level of energy to use before you go into the red. If you have almost depleted the account the previous day, you may start out with the impression that you have plenty of energy in the bank, but will quickly find that you were only just in the black, and go overdrawn early in the day.

Each day you (and only you) have to decide how best to spend your energy quota. Usually it has to be spent on 'basic housekeeping' - eating, dressing, excretion, maybe shopping or cooking. If you want to do something exciting or frivolous - in my case to attend for two hours' practice with my choral group - you allow for this by taking extra rest before or all day, and do not complain if the next day you are overdrawn!

However unwell you may be, you are likely to have a daily pattern to your energy - some wake up feeling reasonably human, but steadily run down as the day progresses. These people need to plan to do essential things early in the day, to make most efficient use of what energy there is. Many others wake up (if they have slept) feeling they would rather be dead, and by later on may improve. For them, things to be done should be arranged for later in the day. It is worth telling friends and colleagues when to call, and when not to bother you. This saves the awkwardness of being incoherent on the phone to someone you'd otherwise love to talk to.

If you are well enough to think of working full or part-time, and this can be arranged, it obviously pays to try and organise your working hours to suit your best time of day. This will be less stressful on both you and your colleagues, as well as more efficient.

Having said all this, I do realise that there are sufferers who find no pattern to their levels of energy at all. However, if you keep a diary of ups and downs and of what you have been doing, then some sort of pattern may well emerge.

Learning to Rest

The more you rest early on in the illness or during a relapse, the quicker you will improve.

Resting, and the giving up of a lot of activities which were part of a busy life, requires discipline. In the past decade we have been bombarded with exhortations to take exercise in order to be healthy. The streets and parks are full of joggers, friends always seem to be planning 'activity' holidays such as skiing, sailing, or walking. We are conditioned now to think that if you sit all day in a chair you will become ill or get 'furred up' arteries, and for a healthy person this may be true. Success tends to be measured by visible achievement; keeping busy is reckoned to be good for one's morale; people who live 18-hour days and appear to be healthy and successful are much admired.

If you have M.E. you must *unlearn* all these conditionings. You will have to learn to be a Mary instead of a Martha, an observer and listener instead of a doer or talker!

Do try and think of the giving-up of activities as something *positive* to do, rather than negative and 'giving in' to M.E. Rest should be regarded as positive, constructive treatment rather than just as 'doing nothing'.

In restructuring your life, you will find that you have to 'spring clean' your priorities, and in fact some aspects of life become much simpler, because there will be fewer choices you have to make. For example: if you do not have the energy (or money) to go shopping for clothes, you will not have to face those exhausting hours and indecision in clothes shops, and as you do not go out so much, the clothes you have will be adequate.

Contentment can come from simple things; the secret of coping is to lower your sights, to *move the goal posts a lot nearer*. Then you will be able to score an achievement more often, with a great deal less effort. Then a walk to the local shop can be as exciting as a weekend walking in the country. A beautiful sunset can be as pleasurable (and cheaper) as a trip to the cinema.

It is important to accept the things you cannot do, and to make the most of what remains. Also to remain optimistic about the future, and to continue to believe that gradual improvement is possible. During the time that you are ill, you must not be too proud to ask for help where needed. Most people like to give and to help, and are waiting to be asked. There may be a forgotten relative who could help, or a lonely neighbour who would be happy to do some shopping or look after the children sometimes. It is worth asking your doctor, or the Citizen's Advice Bureau, about what sorts of help are available, until you are better.

Do remember that your health is more precious than money, and that none of us is indispensable at work. The office, patients, or workshop, will all be there when you get better. So will the possibility of doing other things, even if you lose your job through illness. Many unemployed people, without M.E. or CFS, also have to learn to cope without a job in the present economic decline. Obviously each M.E. or CFS person must decide how best to reorganise life. It is usually a question of sorting out priorities, and your top priority has to be to get better.

I have a scarlet sweatshirt with a motif that reads: *Non Omnia Possumus Omnes*. This is Latin for 'It is not possible to do everything'. I have to remind myself continually of this. It's a good motto for anyone with diminished energy, struggling to get through the day.

Gentle Exercise

In the early stages of the illness, as much rest as possible should be obtained. At this time one should not try to do anything more than the bare minimum. Some people worry about loss of muscle bulk and power from lack of use. In fact the shrinking of muscles is not as great as one would expect, nothing like the wasting that happens in paralytic diseases such as polio. However, if you are ill enough to be spending all day in bed, and if this is likely to be for weeks, then it is essential to do some very simple and non-strenuous movements each day. Every joint should be moved through its full range, to avoid the development of contractures or a stiff joint; and gentle stretching of the whole body should be attempted, as is done by a cat on waking. This can be done yourself, or very gently by a carer.

Suggested Movements

- Shoulders: lift each arm slowly forwards, up beside your ears, back as far as possible, and down.
- Elbows: straighten each arm completely, then bend it so that your hand touches your shoulder.
- Wrists: keeping your forearm still, make a circle with your fingertips, rotating your wrists.
- Fingers: curl them up, then straighten them, then spread them wide apart.
- Neck: starting with your chin on your chest, make a slow circle in both directions, so that your neck bends forwards, then sideways, then backwards, to the other side, then forward again.

- Hips: lying prone or on one side, take your leg backwards, return to starting place, then take it sideways. These movements need not be great, but are important to prevent your hips becoming stiff and bent.
- Knees: gently straighten your legs from time to time, so that your knees are not bent continually.
- Ankles: rotate each foot, first clockwise and then anticlockwise.
- Back: lying prone for a while each day should extend your back. Back tension can be eased a bit by bringing your knees to (or near) your chin, then releasing them again.

The object of these movements is to prevent stiffness or deformity of joints. Most patients will be doing enough each day for this immobility not to become a problem - having a bath, drying off after the bath, putting on clothes, walking round the house. Even if you have to spend much of the day in or on the bed, you should change out of your nightclothes into something else which is warm and comfortable during the day.

There is a fine margin between lying in bed and doing absolutely nothing, losing muscle bulk and tone, and maintaining enough mobility to keep your body supple and maintain muscle tone, while still having enough rest. The other reason for moving around is to keep some circulation going to your extremities, which tend to get cold anyway.

It is also important to aim for some increased activity after the initial period of illness, that is - when the sore throat, fever, muscle spasms and sweating have diminished. Fear of exercise-induced symptoms may prevent a sufferer from ever trying anything new. Do remember that mild symptoms of muscle aching, dizziness and fatigue are inevitable when starting even gentle activity after bed rest that has lasted more than a few weeks. Mild symptoms will settle quickly, and should not be a reason to collapse back in bed. Even if you inadvertently overdo things during a slow increase in activity and have M.E. fatigue and relapse, this will not harm you, and with rest these symptoms will settle down again.

Sleep

This is the best form of rest. During sleep the rate of repair of body tissues is greatest. Animals and children sleep the clock round when they are ill. Many M.E. patients complain that they seem to need too much sleep, but you should allow yourself to sleep as much as you can, it will do nothing but good. If you don't sleep well, you cannot get well.

Unfortunately, a good night's sleep is hard to achieve for many people with M.E. or CFS. All sorts of things conspire to prevent it: muscle or joint pains, oversensitivity to noise, muscle twitching, palpitations, sweating, nightmares, breathing difficulties, panic attacks, and a racing brain that just will not switch off even though you are exhausted.

So, if you have chances to sleep in the day, take them.

If you expect to spend some time awake during the night, have some distraction at hand, such as a radio or an undemanding book, and also something to eat. Try not to fret about being awake; this wastes energy and stops you relaxing.

Suggestions for helping you to sleep:

- Go to bed before you become exhausted and allow yourself time to relax, e.g. with quiet radio or an easy book.
- Make sure your bed is comfortable. If your muscles are very sore, put a quilt, duvet or sleeping bag under the lower sheet. If you are spending a lot of time in bed, consider investing in a washable sheepskin to lie on. The mattress should be fairly soft but not sagging. I have found a good quality latex foam (non-inflammable) mattress better than a sprung one, and also better insulated (hence warmer) - but this is just my personal preference.
- Make sure you are *warm* enough. Chilliness increases muscle tension. An electric blanket is a boon for aching limbs even in summer (but make sure you switch it off before you go to sleep).
- Essential oils, especially Lavender, in the bath or gently massaged into the limbs, really do help. If you can get someone else to do this for you, even better. You can find out more about the properties of various oils by consulting an aromatherapist or reading a book on the subject. It is important to use only oils that are calming or relaxing; those that are stimulating should be avoided. Lavender seems to be good for most M.E. people: it relaxes and calms muscles and balances body energies.
- Avoid exciting or distressing TV, radio, or books in the evening. If one is emotionally fragile, one can weep through the night about some tragedy seen on the news.
- Do not go to sleep hungry, for you will wake up at 2 or 4 a.m. feeling awful - hence the wisdom of having a snack nearby just in case.
- Make sure your bedroom is properly ventilated; there does not need to be a gale from the window, but an airtight, stuffy room does not provide enough oxygen, and may increase indoor air pollution.
- Ear plugs are a boon if you are extra noise-sensitive; they muffle street noises, courting cats, ticking clocks and snoring spouses. The best are the soft wax ones, which soften in the ear, fit snugly, and are non-irritating. They are also useful on a noisy train or bus, or in any situation when noise is an irritation. In summer they can be at hand when sitting in the garden, to put in if a neighbour's lawn mower starts up.
- Avoid having lots of electric cables passing across or near the head of your bed, and if possible switch things off at the plug before sleeping, except for a bedside light. Electromagnetic energy fields may not affect healthy people, but M.E. sufferers seem to be extra-sensitive to them, and sleep disturbance may be one of the effects.
- There are various herbal teas available which are mildly sedative and non-addictive, e.g. Chamomile, and special night-time mixtures. Avoid tea or coffee after 4 p.m. If milk does not disagree with you, then an old-fashioned warm milky drink at bedtime is worth trying. Heated milk contains calcium and natural tryptophan (an amino acid, a component of protein), which are both sedative, and the calories help prevent night starvation.

Sleeping pills are in theory best avoided, as they can lead to dependence on them. However, if nothing else works, and you are suffering night after night and feeling exhausted in the morning, then taking a mild sedative for a few weeks does no harm. Once you start to feel a bit better you may be able to do without them, or take them on the odd night only. A short-acting one like Temazepam (5 to 10 mg) should give six to seven hours of sleep and not make you groggy in the morning.

Some anti-depressants are sedative, and some more than others. For intractable sleep disturbance, which is such a common symptom of M.E., a low dose of an antidepressant such as amitriptyline (10-20 mg to start with) at night can be useful. Sleep disturbance is a common feature of a condition which resembles M.E. called fibromyalgia, and good results have been obtained in a trial of a very low dose tricyclic antidepressant in this condition (amitriptyline 10-20 mg at night). A test of such treatment for sleep disturbance in M.E. is awaited. Some cannot tolerate side-effects of antidepressants, but side-effects are less common when the drug is taken in a very low dose.

In the early stages of the illness or during a relapse, the symptoms that result from doing too much develop within a few hours or the next day. With recovery, the time lapse between overdoing and getting the symptoms (that prove that you shouldn't have attempted overdoing) gets longer, and it becomes more difficult to relate cause and effect. The muscle pain, weakness, sweating or feeling awful may not happen until two days following the imprudent exertion. If you are still keeping a diary it may show you what has caused the relapse. With recovery, the length of time needed to come out of a relapse should get shorter, maybe one week of rest instead of three months; maybe one day instead of a week.

Beware - during the time of gradual recovery, it is very tempting, when feeling so wonderfully well (comparatively), to forget you still have M.E. and to do something stupid like running for a bus or shifting furniture. I know some people whose sudden extreme exertion has put them back to bed for months.

There are various levels of physical rest, ranging from weeks in bed to an hour sitting in a chair. But it is very important to have mental and emotional rest as well. Most of us have a constant chatter of thoughts whizzing around in our brain while we are awake.

If you are used to a busy job (and this includes running a home), then quite likely when you were well you were able to have three levels of thought going on at once.

For example: The most conscious level is holding a conversation; the middle level is composing a shopping list; the deep level is worrying away about some unsolvable problem such as your child's bad school progress. Sound familiar?

With M.E. this sort of mental acrobatics is nearly impossible, and leads to confusion and brain fatigue. The short-term memory goes, so by the time you reach the third item on your shopping list you have forgotten the first two. You struggle wearily upstairs to get something, only to forget what it is you wanted when you get there.

The brain intellectual functions that are affected by whatever it is - cytokines or virus X - that's interfering with the normal messages passing between brain cells are: short-term memory, ability to do simple arithmetic, abstract reasoning, concentration, and interpreting information.

Brain fatigue is as real as muscle fatigue. It is no good trying to force your brain to cope. Many of the circuits and terminals in the computer in your head are out of order; some days more circuits will function than others. Computer experts have coined the term 'virus trouble' to describe some mysterious malfunctions in computer systems - I wonder if these boffins have experience of M.E.?

People with this kind of brain disorder learn to write everything down - and end up searching in exasperation for shopping lists, telephone numbers, etc. I have found no solution yet to the mystery of vanishing lists, nor vanishing clothes, key rings, or tin openers. All this is apparently caused by *not* being able to make memories properly, so a visual imprint of car keys sitting where you put them simply is not filed in the brain. Then, if you have also lost the ability to make associations between things and places, it is not surprising to find the keys in the middle drawer and your pile of clean underwear on the hall table!

The frustration experienced at losing things, or forgetting what they're called, is very wasteful of mental energy, and for previously mentally agile patients this can be harder to bear than the physical fatigue.

If the confusion comes on quickly during the day, it may signal the need for some food and/or a rest. The best thing to do if a sudden fog comes over you is to stop whatever you are trying to do, have something to eat if it is three hours or more since your last meal, and have a little doze. Many M.E. people manage to stay in a job by negotiating flexible hours and arranging for somewhere to rest if their energy suddenly runs out.

The same principle - of stopping before you reach complete exhaustion - applies to brain fatigue as well as muscle tiredness. For months I simply could not cook a meal at 6 p.m., and I struggled and cried over the difficulty of co-ordinating my brain and hands with the cooker, even to boil potatoes. Then I started the routine of a snack at 5 p.m., followed by another rest, which also improved the edibility of the food.

There are various techniques for learning mental rest, including meditation, hypnotherapy, or listening to relaxation tapes (see Chapter 9).

Adjusting

Do remember that when you have M.E., all your functions need to be adjusted so as not to waste precious energy. You need to work out new patterns of behaviour, and to do this effectively you need to listen to what your body and mind are telling you.

One way of looking at the illness is to see it as our body going on strike, and demanding new terms and conditions of employment. Most people with M.E. are by nature highly energetic, and other people tend to look to them for support and enthusiasm. M.E. seems to thrive on these patterns of behaviour.

It may be that a lot of M.E. people will not make any real progress until certain patterns of living have been unlearned, and other more energy-conserving behaviour has been learned.

Getting M.E., or any fatigue syndrome, is a clear message that something is wrong. The illness has forced you to come to a full stop, and fighting what is happening is the worst thing you can do. So give in gracefully, stop fighting yourself and the world; rest, and rest some more, and let the world go by for a time. Unless you do this, the disease is likely to take an even deeper hold.

Case History

The following story is told by a lady who has had M.E. for 22 years, and illustrates the importance of rest:

Miss W. T., now aged 71, retired

'I was first ill in 1970, when I was 49. It was thought at the time to be a virus infection - there were a number of funny viruses around at the time.

'There were years of relapse and recovery, years of weak legs, years of apparent good health, and a steady decline starting in the winter of 1982-83, until the summer of 1985 (when I started to adapt to my life instead of trying to fight it). Since then the only relapses have been when I was in hospital for tests and forced to exercise for physiotherapy or testing. For the last two years I have been able to live at barely 50 per cent of normal life.

'My symptoms are: muscle weakness, which causes me problems with standing, walking, carrying. Fatigue. Pain and jumpy legs at night, sensitivity to noise, inability to concentrate for long; sleep disturbance - my brain may race and I cannot relax, or I may go to sleep, then wake feeling disturbed by a bad dream. I'm also very sensitive to changes of temperature, and sometimes my words get muddled.

'When I am very tired, I am clumsy and irritable, and my face goes a nasty yellow-grey colour.

'I had many medical tests done: for glandular fever (result: normal), for an underactive thyroid - normal, a gland biopsy, repeated tensilon tests - normal, a muscle biopsy - a slight abnormality, repeated electromyograms - mostly normal, one slightly abnormal, a skull X-ray and CT scan - normal, a psychological interview - normal!

'I got almost as many diagnoses as I had tests: 1970, 1972, 1976 - "virus infections"; 1984 - "nothing wrong with you"; 1985 - damage to nerve in muscle, cause unknown; 1986 - nothing neurologically wrong - advised to see a psychiatrist! Later in 1986 - damage to muscle, could be due to earlier virus? 1987 - ME (after 17 years!)

'I worked out that the muscle weakness dated from the old virus infection (1970), but doctors would not listen to me, In 1986 I heard a radio talk about ME, and it sounded like me, I sent off to the ME Association for more information, and I became more convinced, Later I found a consultant who is familiar with ME, who confirmed the diagnosis, without doing further tests,

'In the light of my experience during the last four years, I cannot stress too much the need for rest, and for adopting a lifestyle in keeping with one's limitations, Right from getting the initial virus, I wanted to keep going, and was encouraged to be as active as possible as soon as possible, Since my troubles really started in about 1984, doctors have continually told me to keep going, and even when I was diagnosed as having irreparable damage and told by my GP to adapt my lifestyle and keep within my limits, the neurologist was still assuring me that I must *not* rest, I must keep as active as ever possible,

'It was during the time that I was fighting against the weakness, and dragging myself about in an effort to keep going, that my condition deteriorated so fast and so permanently, As soon as I modified my life and listened to what my body was saying and kept within my limits, whatever anyone said, it was amazing how the deterioration slowed down and almost stopped,

'The ME Association theory is that rest in the initial stages can be a big factor in recovery. I never had that rest. And now, I cannot help wondering whether, if I had been advised to rest even in 1984, instead of being instructed to keep going, I might not have the permanent damage which has now occurred.'