

Chapter 19

Finance and Practical Problems

It is bad enough to have a disabling disease that causes pain and exhaustion, but many people with M.E. endure the added stress of financial hardship, through being unable to work. Many are highly motivated, hardworking, self-reliant people, to whom the idea of accepting State benefit may have been unthinkable before natural retirement.

Employment and State Benefits

When you first become ill you may be in an employed position, and therefore eligible for sick pay. If you are self-employed, you may be able to get Sickness Benefit.

The real problems arise if you are still ill after six months (28 weeks), at which point you and everyone else start to wonder how long this is going to go on for. If you are making some recovery it may be tempting to try going back to work. If the job is full-time, and physically and emotionally demanding - such as nursing, or teaching - the chances are that you quickly find out that you are *not* fully recovered, have to stop work again, and have a major relapse brought on by the exertion. No one can predict at this stage if you will need a further six months off, or a year, or more.

You must accept that *your health comes first*, and if you need more time completely off work, that is what has to happen. Some people may be able to negotiate part-time work, with the flexibility of going home or resting should their energy run out. But these kinds of jobs are rare. When considering whether or not to stop work completely, you need to ask yourself if the job is going to hinder further recovery, or if you can manage to improve despite the job.

It may turn out to be possible to work, but only if a lot of other activities are given up, and if someone looks after your domestic needs - shopping, preparing meals, cleaning and laundry. For some people, getting back to some sort of work, even if part-time, will have positive results in terms of their mental well-being and will remove the threat of isolation, feelings of uselessness and invalidism. A return to part-time work may end up paying for home help, child care, etc., leaving no money to spare but offering great psychological benefits because you are able to return to the world. But if there is any doubt about your ability to return to work without having a relapse, think carefully.

I struggled for a few months, working only one morning a week to maintain a minimum income, and found that it took all week to get over the exhaustion caused by one day of light work. Once I decided to stop completely and make the commitment to getting better, some slow recovery started.

A lot will depend on whether you are self-employed and therefore your own boss, or, if employed, on the attitude and sympathy of your employer. You should also consider whether you can really be effective in your job if you are still unwell. It may be that

clients, pupils, patients or colleagues suffer on those days when you are struggling and mentally under par, even though *you* may believe you are doing a tremendous job. Do not be too proud to claim state benefits.

Do not think your presence at work is vital for the world to go round.

Remember there are thousands of other hard-working, conscientious and clever people just like you who have had to stop working because of illness; you are not unique.

See if there is a way of working part-time, with the flexibility to rest or go home if you feel ill. Access to a couch somewhere at work, to have a sleep midmorning or midday, may enable you to stay in your job.

What if your work is unpaid, and is essential? I am of course referring to that underrated profession called 'housewife/mother'. The reasons for stopping work and resting apply to you as well, but the practicalities are difficult. If you cannot run your home, shop, or prepare meals, the Social Services Department may be able to arrange a home help, especially if you live alone or are a single parent. You may be entitled to a home help even if you are supported financially, if your husband or partner has a busy job and is out most of each day.

If you require help with dressing, washing, meals, etc., you can claim Attendance Allowance. And you can claim this even if there is no one looking after you.

Someone who stays at home to look after you and who therefore cannot go to work may be able to claim Invalid Care Allowance.

If you have young children, and have no one to take them each day while you rest, Social Services may be able to arrange a child-minder for a few hours a day.

You can be assessed by someone from Social Services who will visit you at home. When you are being assessed and questions are being asked, remember how you are at your *worst*, even if the visit takes place on one of your better days. Be quite definite about how much disability the illness is causing. It is no good saying 'Sometimes I can stand for long enough to wash up' if this is the exception rather than the rule. The problem with M.E. is in convincing people that your energy evaporates very quickly and is insufficient to provide for the most basic needs of living. You must describe yourself as you are at your worst, and not minimise or be apologetic about your disability.

Wheelchairs

You do not need to be totally unable to walk to consider getting a wheelchair. A wheelchair, plus someone to push it, can open up horizons for you if you cannot walk very far. You can potter round a shopping centre, visit art galleries, stately homes, or go for an outing in your neighbourhood. Trips away, holidays, all sorts of journeys may now be possible with a wheelchair. Apply to Social Services, or the Red Cross for the loan of one.

Caution - do not wheel the chair yourself.

M.E. affects the arms as well as the legs, and the wheelchair is meant to conserve your energy! The helper who pushes you will need a few practice sessions away from a busy road or pavement. A common mistake for the learner-pusher is to allow the chair to tip forward when going off a pavement, risking the occupant falling out. To negotiate pavements, steps, or bumps, the chair is tipped back so the weight is all on the main wheels. The other main rule in the wheelchair code is *brakes on when parking*. Your pusher needs to be reasonably fit, as well as willing - wheelchairs can be hard work, especially on uneven ground.

Many M.E. patients whose walking is quite limited shy away from the idea of a wheelchair, because they do not want to become, or be seen as, an invalid. Being an invalid is partly a state of mind and partly a way other people perceive you. Better to see the wheelchair as a useful tool to help you get out of the house and join in the rest of the world at times. When you have a remission or get better, you won't need it.

Walking Assistance

The best aid, other than a wheelchair, is a folding stool-stick which can be used as a walking aid and then unfolded easily into a seat when needed. It is absolutely invaluable if you get collapsing, aching legs when having to stand for any time. If you are halfway round a supermarket and feel dreadful and shaky, you can park yourself on the stool for a few minutes - also at the checkout, in queues in the bank, at bus stops, and railway stations.

This gadget is *not* the same as a 'shooting stick' which has a sharp point to go into the earth and a very small seat (devised to sit on while you watch others shoot game birds). These are quite unsuitable, as the sharp point will not stay put on a shop floor or pavement. The best stool stick is sturdy, with four non-slip rubberized feet and a strong canvas seat, and is made in different heights.

Stool sticks are obtainable from various retail outlets, including National Trust Centres, and some sports shops - those that supply things for hunting and shooting.

Travel

It is possible to go away on holiday with M.E., but obviously not while acutely ill. For some, a change to sea or mountain air, the sun, and new horizons may be enjoyable and benefit the health. For others, especially those who get vertigo and visual problems from movement, the journey may be too uncomfortable, and the need to adapt to new surroundings, a different bed and a new daily routine may be too much to cope with.

Air travel may seem quick and simple, but in practice it is the most stressful form of transport since the days of the bumpy stage-coach. If you decide to go for a holiday by air, it is wise to choose a time of year out of season, and to avoid those airports that are notorious for congestion or delays. It may actually be worth paying extra and travelling on a scheduled instead of a charter flight.

If you are unable to walk or to walk far - distances on foot at airport terminals may be ¼ mile or more - ask the travel agent, or the airline direct, to arrange a wheelchair or buggy. This will then be organised again at your destination airport. This needs to be arranged in advance, and confirmed a day or two before travelling.

In theory this all sounds fine, but beware of Gatwick Airport's North terminal! Opened in 1988, modern, with arcades of dazzling shops and piped 'musack' this new terminal is a nightmare for the disabled, and indeed for anyone with a mountain of luggage and/or small children. Wheelchairs and luggage trolleys are not allowed on the inter-terminal connecting monorail train - they have to be left behind about 30 yards before entering the train. If you are lucky, someone different will meet you with another wheelchair at the other end. If you have a lot of luggage, tough. It is quite hard to find another trolley when you leave the monorail train.

Having researched this airport and its North terminal recently, going on a holiday to Greece, I heartily advise against using it unless you can contact the airport authorities in advance and find out if the rules have changed or if they have now arranged means for a disabled person to arrive at the plane without having to change wheelchairs and walk!

The other disadvantage of air travel, apart from the stress and noise, is the level of chemicals in aircraft and terminals. If you are chemically sensitive, then you may feel quite unwell for a day or two after the flight. Some sufferers are adversely affected by the drop in pressure in the aircraft (this may particularly affect those with breathing problems).

Side-effects of air travel, or indeed any travel where increased exposure to chemicals and stress occurs, can be helped by taking extra vitamin C (1-3 gm) before and during the journey, and by drinking plenty of water.

Travelling by train is probably better than by air, or coach, or car on long motorways. British Rail issue Disabled Persons Railcards, which provide a discount of 30 per cent on railway tickets for both the holder plus an escort. If you receive Mobility Allowance or Severe Disablement Allowance, you can apply. If notified in advance, BR staff will help you on the train and meet you with a wheelchair or 'buggy' at the other end, which whisks you through the crowds in comfort to a taxi or, if someone is meeting you, to a waiting car.

There is an informative leaflet, *British Rail and Disabled Travellers*, available from BR stations. If you do not drive, cannot afford to run a car, and do not have a carer or relative to drive you, then rail transport for long journeys is relatively painless, provided you ask BR for help at least a day in advance, and do not travel just before a bank holiday, or during school half-term!

When travelling, and if using assistance, do not try and walk some of the way - the staff will not understand if you say you can walk a few yards but get tired. The type of disability produced by M.E. is very difficult for most people to understand, especially as we don't have crutches or callipers.

A problem encountered by some in long car or coach journeys is that of petrol or diesel

fume pollution entering the vehicle; this is worst of all on busy roads or in traffic jams. A car with a filter at the air intake may help, but these are rare. It may help to be aware of this problem, and close all windows and vents when stuck in slow-moving traffic.

The decision on whether or not to travel, and how, is a very individual matter. But the opportunity to travel and escape from four walls should not be dismissed out of hand. A journey will need much more planning and thought than it did when you were well, but is still possible. I know of at least two M.E. sufferers, both hardly able to walk, who have had enjoyable trips abroad with the help of a wheelchair, other people, and schedules that still allowed plenty of rest.

House and Garden

There are lots of ways of making home life easier. Most energy-saving ideas come from fellow-sufferers, and in every copy of your local M.E. Society's newsletters you will find many helpful ideas. In the home, several obvious possibilities are:

If your bed is not on the same floor as the bathroom, have it moved there if you are in a bed-resting phase.

Do everything in the kitchen sitting down, if possible, by arranging a chair near a work surface for food preparation, and using a high stool at the sink for washing up, raising the washing-up bowl to the same height.

Collect everything in one container that you need for preparing a meal, e.g. washing-up bowl, or basket, and take them to the work area before sitting down.

Iron sitting down, or do not iron at all; there is very little that really needs ironing, or cannot be ironed by someone else.

If your finances allow, consider investing in a machine that chops and mixes food - a food-processor. Chopping vegetables can be exhausting, and the temptation would then be to live on toast and tinned food, which are not good for you.

If you are spending a lot of time in bed and are well enough to talk on the phone, get a phone extension (which you can switch off) by the bed. There are telephone aids for disabled people; a shoulder rest to save you holding up the receiver is very helpful. Have a very comfortable armchair in the bedroom by a window, ask someone to fix a bird table within view, and get some binoculars. Make your bedroom cheerful, warm, and homely to be in.

In the bathroom, have a stool or chair to sit on while drying after a bath or wash, or while undressing. If having a bath is too exhausting, a stool or chair under the shower is a solution. If there is no shower, try sitting on the stool in the bath, and have a bowl of warm water on a chair next to the bath. Scoop the water out with a large unbreakable container and slosh it over yourself, or ask your helper to do this for you. You can wash all over and rinse while sitting down, and feel fresh and clean afterwards. (In countries with limited water or no plumbing, this is the normal way to have a warm shower!)

Make sure the bathroom is warm for this all-over wash. This 'two chairs and a bowl' method is much less exhausting than a bath or standing by a basin. A non-slip bath mat is essential for any method, especially if you have problems with balance or co-ordination.

In the garden, have a very comfortable seat at hand, such as an adjustable sunbed, to lie or rest on. Doing gentle gardening can be very therapeutic to the soul if one is well enough, and it gets one out of the house into the fresh air and light, but there must be somewhere to rest at frequent intervals. There is a gardening stool for disabled people available, which one sits in and is still able to weed or use tools at ground level. A local garden supply centre should have details on such an aid. Even in a wheelchair, it is possible to work in raised beds and borders. Sowing and 'potting on' can be done in a greenhouse from a chair.

The main enemy action in the garden is bending over or crouching, which places great strain on your thigh and back muscles. Sitting on newspaper or other waterproof layers beside a section of plant bed is preferable.

Keeping Warm

Keeping warm is very important. In M.E. the circulation is usually bad, the body's thermostat doesn't work properly, and a lot of energy can be wasted in fighting the cold - energy that is needed for other vital functions. Nor is the problem confined to the winter, at least not in the UK, where temperatures can drop low enough to require heating, hot water bottles and electric blankets from June onwards throughout summer.

Remember to keep your feet warm at all times, and that 30 per cent of body heat is lost from the head. A woolly hat may be helpful, not only for outside, but in bed at night, or while indoors in cold weather. Several thin layers of clothes are always better insulation than a few thick ones, and extra layers should always be at hand to put on wherever you are, especially if away from the house. A sudden feeling of chilliness can strike at any time, regardless of the weather, often due to a drop in blood-sugar, or rapid exhaustion; your body temperature may bear no relation to whether you feel hot or cold! A sudden attack of iciness may mean you need to have something to eat, and to have a sleep.

Just because others in the household may be comfortable in shirtsleeves doesn't mean that it is warm enough for you. But rather than turning up the central heating (70°F / 21°C) is the maximum advisable), you should wear more clothes and pay attention to keeping your head, feet, and neck warm. It is still important to have some ventilation in the home, even in cold weather.

In cold weather it is sensible to have a stock pot of soup or a stew on the go. This supplies instant hot food with minimal time to be spent in a cold kitchen just before a meal. Certain foods have warming properties, such as ginger, cayenne pepper (caution - you only need a pinch), most curry spices, peppers, garlic, and brown lentils. These foods will warm you whether they are taken hot or not, and are good to include in stews or soups.

Heated mini-blankets, or heat pads, are a good way to supply warmth to the back, chest or tummy as needed if you are cold and have stiff or painful muscles. An electric blanket is marvellous for providing instant warmth when you get into bed, all the year round. Do make sure it is safe, though, and do not leave it switched on if it is an under-blanket.

A warm bath or shower is good for warming, also for improving circulation and lymph-fluid flow and for removing waste products that the body gets rid of through the skin via the sweat. Many people forget that the skin is an organ that eliminates toxins and body waste, so sweating a lot when you are ill is not a bad thing. The kidneys, skin, colon and lungs all get rid of waste, plus water, which needs to be replaced in ample amounts.

However, a hot bath (over 99°F/37°C) is *not* recommended if you are ill, weak, or have any heart symptoms, because of the extra strain the excessive heat puts on the circulation. Unless specifically advised as part of hydrotherapy treatment, bath water should not be hotter than body temperature.

Part of the benefit of a bath or shower comes from a rub down all over when drying: this stimulates circulation of lymph, the fluid carrying the white cells. Drying yourself may be the most exhausting part of the washing process, and you may need to ask for help with this if there is much muscle pain and fatigue. It's better to forget modesty and have some help, rather than forego a regular bathe which does much good to morale and body.

Many additional helpful hints will come from other M.E. people whom you meet or telephone through local groups. As someone said, necessity is the mother of invention! Only someone with the same problem as you can really advise you on how to solve it.