

Chapter 21

Caring for Someone with M.E.

The illness of any member of a family inevitably adds to the strain on relationships within it. If someone has an acute illness, or an injury, or an operation, there is an expectation that he or she will get better after a predicted period of convalescence, and will return to more or less normal life. So the period of upheaval is seen as temporary, it has some sort of boundary; the illness or operation is usually definable and recognised, and the whole period of illness and recovery can often be coped with.

But if having M.E. is a sentence of unknown length, with no remission for good behaviour for the sufferer, it may be an equally long sentence for the people closest to the patient.

A lot of the difficulties with M.E. that result from adjusting to living at home, in one's community, rather than in hospital or in a nursing home, also apply to other chronic disabling conditions. The strain of caring for someone with heart disease, multiple sclerosis, a stroke, kidney disease, or cerebral palsy (there are many others) is no different from that of caring for a badly affected M.E. sufferer.

However, what makes the M.E. syndrome different is the *variability* and *unpredictability* of both the patient's physical state and mood. As a carer, one day you may rejoice to see the patient happily doing a little gardening, yet the next day may find you helping with dressing and washing. One day there are hours of sobbing and anguish, the next there is a calm person who does not realise what a dreadful day he or she gave you yesterday.

The unpredictability of M.E. makes planning for the future difficult. By the time the diagnosis is made, the patient has probably been unwell for six months or more. Can one confidently go ahead with plans that affect the household such as moving house, holidays, renovations, or job changes?

Fear of the future is always worse than the reality of today. There is probably a better chance of peace of mind if no long-term plans are made which cannot be unmade; living from day to day and letting the future take care of itself is to some extent a good philosophy for M.E. families.

In reading about relationships, the assumption may be that a man-woman relationship is referred to. I am, however, taking relationships to include those between friends, neighbours, and other relatives, as well as immediate family. By 'carer' I mean the person or persons most closely involved with providing practical and emotional support for the M.E. patient, be they spouse or neighbour.

In any close relationship there is a tendency for the emotional mood of one to have an effect on the other. If one person is sullen, withdrawn or depressed, the other thinks 'What have I done to cause an upset?' It is so natural to take the emotional moods of a loved one as a reflection of how he or she feels about us, and so very difficult to be a detached, though caring, observer.

So, if you are a carer, try and remember that your patient's rapid emotional changes are due to the illness, and not to changed feelings towards you or diminished need of you.

Because the life of the carer, as well as that of the sufferer, may be disrupted, this can lead to resentment on the part of the carer, and guilt for the sufferer. But both sides try desperately not to let these natural feelings show. Guilt at being 'such a burden' is common, and of course it just adds to all the mental suffering already experienced. The assurance of being loved and valued as a member of the household, in spite of being an apparently useless wreck, can reduce the guilt.

The resentment felt by a carer at having his or her own life disrupted by this interminable illness is a common emotion, and should not be underestimated. The carer then feels guilty about this resentment, cannot express it for fear of upsetting the patient, and so ends up irritable and moody. It is in this situation that a once open, loving relationship between carer and patient can deteriorate.

You as a carer may experience feelings of anger, resentment, frustration, or grief for many reasons: because a loved one is ill and you don't know when he or she is going to get better, because both your lives are turned upside down, and because you may have to sacrifice your own job, time, hobbies or holidays in order to be able to care effectively.

These feelings are perfectly normal; you are not born to be a saint! What is wrong is to bottle everything up and do damage to yourself, the patient, and other members of the household. But carers need support as well, and it may be helpful to talk to other carers, or to anyone offering a sympathetic ear, if you feel you can't cope with the illness and the patient.

Sadly, a number of relationships do break down completely under the stresses created by M.E., leading to separation, divorce, loss of a lover or close friend, or children leaving home. I do not have the skills necessary to advise on how to prevent these separations; they happen to many people without M.E., but are harder to bear if a chronic illness is the main reason for the split.

Sometimes a relationship has been going wrong anyway, before M.E. appeared, and in such cases a severance may *remove* a major stress, and later allow the patient a better chance of getting better. However, sometimes the human resources of loving and understanding develop in two people as a result of one of them getting M.E., and a lukewarm relationship may then grow into a much deeper and warmer one.

Possibly one of the most important aspects of some relationships to suffer is a sexual one. I do not think that a lessening of sexual desire is something confined to M.E., but may be a symptom present with many chronic illnesses. After all, becoming ill is a sign that the whole body-mind complex is not functioning properly.

A sick animal or child rests, following the body's need to conserve energy for healing. A sick adult human also stops expending energy on unnecessary activities. Sometimes there is not enough energy for digestion or for talking, so the body is certainly not going to give much priority to the act of lovemaking! In women who are ill, loss of interest in sex may be a protective mechanism (unconscious) against becoming pregnant while the body would be unable to cope with it.

The loss of sexual desire is a very common symptom with M.E., but is not something that people talk about readily to the family doctor. There are, of course, other ways of expressing affection as well as the sexual act itself. Some couples may succeed through compromise, such as finding occasions when the fatigue is not so great; using different techniques or positions; or perhaps by accepting that this one part of the relationship may have to be put aside for some time. Mutual understanding of why the problem arises, and accepting it as just another activity to forego for a while just as one has to accept that long walks, late nights, socialising, etc. are activities to be postponed until the patient feels better - are ways of coping with this problem.

It is enormously helpful for the M.E. patient if the carer can demonstrate that he or she believes the patient has a genuine illness, and at the same time demonstrates the belief in possible recovery. It can be a bit difficult to draw the line between being supportive and helping in every aspect of living when needed, and in encouraging the patient to be an invalid.

There are times when the patient needs to be allowed to stretch his or her wings and try and do a bit more, and times when the carer needs to be firm and say 'That's enough, you must rest'. Balancing the functions of a protective nurse and a occupational therapist can be tricky even when looking after an illness which is predictable. With M.E., playing it just right is nearly impossible when your patient is so unpredictably up then down.

Here is some advice to the carer, given by someone with experience of this challenging job:

- The M.E. carer must have patience, compassion, resilience, and belief in M.E. as a mentally and physically crippling disease in varying degrees.
- You have to learn not to mind when people tell you you are being exploited by waiting hand and foot on someone who usually looks perfectly fit, e.g. in a wheelchair one week, and next week walking.
- You need to be aware of the varying limitations of the M.E. patient and be ready to step in, such as rescuing a patient from long and exhausting telephone conversations.
- Be prepared to help in all aspects of daily living, as required.
- If the M.E. patient, in desperation, behaves out of character, do not take it to heart, and learn not to be thrown by wide mood swings.
- Try to maintain the fine line between having a life of your own and yet still realising the extent to which you are needed for moral as well as physical support.
- *In short - be a perfectly perfect person!*

Carers often feel isolated, and need help and support. Most people do not know exactly how the Health and Social Services work; if you or the person you look after need outside help, you

may not know how to go about asking.

There are three sources of help to try first:

1. Your family doctor

Do not neglect to tell your GP about your own health problems - a sick carer is entitled to medical help just as much as the patient. Ask about any help which may be needed with lifting, dressing, or bathing the person you care for.

A district nurse may be asked to call and give advice.

2. The hospital

If the M.E. sufferer is in hospital or attending an out-patients clinic, ask the specialist to explain any disabilities.

Many M.E. patients prefer to avoid hospitals, though, as not all doctors and nursing staff understand what the illness is, and may want to institute physiotherapy. Hospitals on the whole are not good environments as regards getting plenty of sleep and avoiding chemicals!

3. Social Services

The phone book gives the address and number of your local Social Services. You can ask: for a social worker to visit the home to find out what the patient's needs are, for information about what is needed, and what home help is available.

This last case history is of someone I have met. She and her family have shown great courage and patience for the 4½ years of her illness.

Clare's Story (told by her mother)

'In December 1986, Clare was a second-year university student, doing Psychology and English Literature. She lived in Halls of Residence, was generally fit, and enjoyed dancing and other active pursuits. On the morning of the 6th December she woke with what seemed to be flu. She returned to our house, spent eight days in bed, and felt exhausted. However, she seemed to recover, did her end-of-term exams, and felt reasonably well over Christmas.

'The flu returned on the 2nd of January '87 and, because she felt so exhausted, she went to the doctor on the 6th January. The GP took a blood test which showed a high antibody titre to Cocksackie B virus. Clare then returned to Halls, feeling decidedly more tired and much slower in her actions, some nights having to go to bed after tea. Another visit to the doctor and another blood test - this time there was no high Cocksackie antibody. In the meantime I had read about M.E. and asked if this was a possibility. The GP totally rejected this, told Clare she had a post-viral condition, that she should continue with her studies but not take any strenuous exercise ("Aerobics maybe, but squash no!").

'During the period from February to the end of the second term, Clare's condition worsened, with only a few brief spells of remission. She had greatly slowed down, couldn't imagine

walking very far, and was generally behind with her studies. During the Easter holidays she decided that she could no longer continue as a student, and notified the university authorities on 23rd April 1987.

'Around this time her GP referred her to a consultant at Ruchill Hospital who gave her a diagnosis of Post-viral Fatigue Syndrome or M.E. and estimated that it might take anything up to three years to get better.

'Gradually Clare ceased to be able to get up for meals. She began to experience what she called "a wobbly head" - a frightening feeling where her brain seemed to be losing contact with her eyes. As well as the intense fatigue, other symptoms appeared in the following months - cold, almost wet feet, a sensitivity to light, with after-images, and sensitivity to sound combined with a ringing in the ears, culminating in a severe and constant headache in September.

'Any kind of stimulation seemed to produce pain for her. She was no longer able to tolerate visits from friends, and could have only limited contact with her family. Having a bath or washing her hair was beyond her. She suffered intense malaise and often felt that she was dying. From this time on her mobility disappeared, and she had to be pulled to the bathroom on a chair with rollers. Some days she was unable to sit up for meals and had to be fed.

'During this period Clare's father and I, in increasing desperation, sought help from various sources. A herbalist recommended an anti-Candida diet, which after five days made Clare feel very sick and caused vomiting. It also made her lose half a stone in weight, which, combined with the loss of muscle bulk, left her weight at 7 stone. She discontinued the diet as she felt unable to cope with the nausea and further weight-loss.

'In July a three-day stay in a homoeopathic hospital was equally unsuccessful. She returned home with a promise to the doctor-in-charge to continue on a wheat-free diet for some six weeks (which she did), and to try and sit on a chair for ten minutes per day, which she was unable to do. A physiotherapist was sent from the local hospital, but even sitting out on a chair for more than a few seconds caused Clare to break out in severe sweating, so this was discontinued.

'Autumn 1987 came round and Clare's symptoms were at their worst. She lay all day every day in a room with the curtains drawn and with wax plugs in her ears. An eczema-type rash developed on her face and was only kept at bay by daily applications of cortisone cream. The encephalitic symptoms were predominant - constant severe head pain, a sense of unreality, and nightmares. Another homoeopathic doctor, whose speciality was "psionic medicine", was contacted. In all telephone calls and letters he promised "a significant return to health in the very near future' '. After three months and no sign of recovery Clare's disillusionment was intense. Reflexology was equally futile.

'In January 1988 Clare was able to have the curtains opened - an hour a day initially, then throughout all the short winter days. She also decided to dispense with all diets, keeping her food balanced and additive-free (and cut out all chocolate, which she found had a bad effect on her). There had been no proof that the diets had helped her, and she felt her life was restricted enough. During March/April her headaches were as bad as ever, although her sensitivity to noise had abated somewhat.

'In April 1988 she heard that injections of Parentrovite were being tried with some success by an immunologist in Belfast. With the agreement of her GP Clare had six fortnightly injections which did seem to help her condition somewhat.

'She could now watch television for short periods, listen to the radio, have a bath and wash her hair once a week. She no longer needed her ear-plugs, and could cope with much more family input. The headaches and the ringing in her ears were still there, but were more intermittent and not so severe. This improvement was not dramatic, and was in fact imperceptible on a day-to-day basis.

'She then began taking amitriptyline, one of the tricyclics, to combat panic attacks (a *Horizon* TV programme suggested that it might be useful in some M.E. cases). Initially there were some side-effects, but these were outweighed by an overall improvement in her condition.

'However, after a year and a half in bed Clare was still unable to walk more than five steps, and her full recovery seemed a long way off.'

Postscript

'The following two years saw Clare make some progress, to being able to get up a little each day, being less sound- and light-sensitive, and able to watch TV and speak on the phone. However her muscles were very weak and she was still mostly bedridden, and an increasing feature was anxiety/depression. A weekly visit from a psychotherapist seemed to do more harm than good. In October 1990 Clare agreed to accept treatment in the Psychological Medicine department of a local hospital. The doctor in charge took the view that M.E. is an organic illness, and was interested in alleviating symptoms.

'Clare stayed there five weeks, coming home two weekends. To begin with the staff didn't seem to do very much, and encouraged but didn't force any activity. They also changed her antidepressant to Clomiprimine. Despite the alien hospital conditions (patients smoking, lack of good sleep), we did notice a change in Clare over the time she was there. When she came home she began to try more things going out in a wheelchair at first, then for short walks. She has gradually increased this activity and can go into town and for short trips in the car (she has given back the wheelchair). She still suffers from head pain and exhaustion, but nowhere near as severe or long-lasting as they once were. She also has big emotional troughs, and sometimes it seems harder for her to cope with the frustrations of being half well than it was when she was completely incapacitated. She hopes to return part-time to university in October of this year, but some days this seems unlikely.

'I want to emphasise that she still has M.E., but maybe there was after four years some psychological element that had to be overcome before she could continue her progress to recovery.'