

## Contemporary Themes

# Common psychological problems in multiple sclerosis

ALEXANDER BURNFIELD, PENELOPE BURNFIELD

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In an earlier paper one of us (AB) described his personal experience of multiple sclerosis (MS).<sup>1</sup> Over the last two years we have taken part, singly and together, in the counselling of other sufferers from MS and close relatives. This voluntary work has been informal and much of it has taken place in our home. We discuss here some of the emotional difficulties created by MS and our observations derived from counselling and from participating in self-help groups stimulated by CRACK (the young arm of the Multiple Sclerosis Society).

### Organic symptoms

The physical effects of MS can produce psychological symptoms, including mood swings, poor concentration, and irritability. In the more advanced stages of the disease some degree of dementia is common.<sup>2</sup> Euphoria has traditionally been associated with MS, but this may mask underlying depression and act as a defence against an intolerable situation. Organic symptoms seem to be commonest in patients suffering from the severe progressive form of the disease, in which cerebellar lesions predominate. Many patients who are not severely disabled by MS, however, seem to remain clinically free from organically determined psychological symptoms.

### Emotional problems

Emotional reactions to MS are inevitable, as in any other chronic disease, and they often have serious effects on the patient and his family. In many cases they may be responsible for a handicap in terms of suffering that is greater than that caused by the physical effects of the disease. Emotional disturbance may be particularly severe and prolonged if the patient fails to receive adequate counselling and support.

### Learning the diagnosis

We have often been surprised by the ways in which many patients had learnt that they had MS. Some said they had been given little time and consideration from their doctors, and few had been encouraged to learn the facts about MS. Patients often claimed to have learnt their diagnosis indirectly. A few had read their medical notes upside down on the doctor's desk, others had steamed open letters entrusted to them by their doctor, some had found out by accident from hospital staff who assumed that they already knew, and

sufferers had occasionally diagnosed themselves after talking to other patients in a ward.

Doctors often prefer to deal with diseases that they can cure rather than spend time on what some perceive as hopeless cases. This attitude has been encouraged in the past by the pattern of medical education, though it is slowly changing. It is not surprising that some doctors feel uncomfortable when confronted with MS. They often have an unduly pessimistic view of the prognosis, based on hospital rather than community experience. They may be unprepared emotionally to cope with either the patient's problems or with their own feelings of inadequacy. As a result, they dislike discussing the disease with the patient and may rationalise that it is best for him not to know the diagnosis. Sometimes the doctor will give the diagnosis to the husband or wife with instructions that the patient must not be told. This can place an intolerable strain on both partners, damaging their relationship.

Many patients have told us that much of the anxiety and depression experienced before they learnt the diagnosis was dispelled on discovering the truth. They felt relieved, especially when they had been imagining something worse, such as a brain tumour or "going mad." They could gain strength from the increased security of knowing where they stood.

As there is no reliable diagnostic test for MS, the diagnosis cannot be confirmed until some time after it has been suspected. By this time the patient often feels anxious and confused. In our experience it is important for the patient, together with a close relative, to be told the diagnosis once it is known for certain. The level of information need not be too complicated at first, but patients should be given the opportunity to return for further facts and emotional support. Some general practitioners can offer skilled counselling, but others may want to delegate this responsibility to a health visitor or community nurse. It is important at this stage to tell the patient about his local branch of the Multiple Sclerosis Society.\* This will have an experienced welfare officer, who will be able to visit the family at home. Joining the society is also a positive step for the patient, who can then feel that he is doing something constructive for himself and for others in similar circumstances.

Another useful organisation is Action for Research into Multiple Sclerosis,† which provides a London-based telephone counselling service for sufferers and their families. It is sometimes helpful for the patient to meet someone with MS who has successfully worked through similar difficulties. This may be an informal arrangement or take place in the setting of a self-help group. Some people, however, are unwilling to meet others with the same condition until they have worked through their initial feelings of anxiety and have started to adjust on their own.

### Coming to terms

The patient is often shocked on learning the diagnosis, even if he has suspected it. He may react with severe anxiety, anger, or denial. Later many sufferers become depressed owing to their feelings of loss. Normally they will slowly adjust and establish a new identity based on a realistic acceptance of their limitations. This process parallels the response to bereavement and may last a long time. It is a normal psychological reaction and should be neither discouraged nor over-

\*Multiple Sclerosis Society, 4 Tachbrook Street, London SW1V 1SJ.

†Action for Research into Multiple Sclerosis (ARMS), 71 Grays Inn Road, London WC1X 8TR. Telephone counselling service: 01-568 2255.

Child and Family Guidance Clinic, Winchester SO23 8AD  
ALEXANDER BURNFIELD, MB, MRCPsych, medical assistant in child psychiatry

Winchester and Central Hampshire Health District, Winchester SO23 8AF

PENELOPE BURNFIELD, MB, BS, clinical medical officer

indulged. The sufferer from MS needs to express freely his natural feelings, which may be therapeutic in itself. If the experience of loss is not expressed bottled-up feelings may cause serious problems later, such as depression and relationship difficulties.

### Invisible symptoms

In the early stages of the disease, and sometimes for the whole of the patient's life, the effects of MS may be invisible to others. Common invisible symptoms are fatigue, visual handicaps, and difficulties with bladder control. The presence of these invisible symptoms may cause anxiety, and the patient may not know whether to perceive himself as "disabled" or "fit." He may alternate between the two roles, depending on domestic and work circumstances. Sometimes he fails to make allowances for the disease and continues his denial by working too hard or by engaging in stressful activities to prove that he is "normal." He may think that if he mentions his tiredness or subjective symptoms he will be regarded as a hypochondriac or as a malingerer. All too often these fears are justified and he may fail to obtain much understanding from his family or employers if he looks fit and healthy.

Premature fatigue is one of the least understood symptoms of MS. Many sufferers are free of symptoms when at rest, but physical activities, such as running for a bus or mowing the lawn, can bring on blurring of vision, unsteadiness, heaviness in the limbs, and a sensation of extreme tiredness. This tiredness seems to have a quality of its own but it is similar to the fatigue that occurs in influenza. The phenomenon is hard to communicate to others and is often attributed by doctors to neurosis. The effect of this on the patient is to generate real neurotic symptoms, which then confirm the doctor's original suspicions. Fatigue is also produced or exacerbated by warm weather or hot baths. It occurs more continuously just before and during a relapse.

### Obvious disability

People who have more advanced MS and whose disability is obvious to others have different psychological problems. It is easier to accept being part of the disabled group in the community, but the sufferer must come to terms with the stigma of MS. This leads to a change in body image and he may come to see himself as no longer useful or attractive to others. This poor self-image can cause him to fear rejection by his partner and he might become unreasonably jealous, especially if there are sexual problems.

It is difficult to get used to having a stick, and some people with MS try to do without, even when this is dangerous. Similar problems arise with wheelchairs; patients may find these humiliating, especially if they have overvalued their independence. Others seem to accept the wheelchair and a dependent role too readily. Both these responses are unhealthy when taken to extreme, but counselling at the right time can help to develop a more positive and realistic acceptance of the condition.

### Family problems

MS can cause considerable unhappiness within the family, especially between marriage partners. If the basic relationship is poor MS may be made a scapegoat for all marital or sexual problems. This may lead to separation and divorce. The sexual problems associated with MS are not necessarily due to the physical effects of the disease, unless disablement is severe. Problems are more likely to be due to anxiety, poor self-image, and depression. Patients may find it useful to contact the Committee on Sexual Problems of the Disabled (SPOD),\* who provide specialised information and advice.

Marriage partners may find it difficult to express feelings of anger, which may lead to lack of communication and misunderstanding. The MS sufferer may fear that if he makes demands of his partner she will reject him. On the other hand the partner may find it difficult to express anger if he or she feels guilty about being the healthy one. These relationship problems are common and require skilled counselling if they are to be resolved.

Some sufferers fall too readily into the sick role, which they use to manipulate their partners or other relatives by inducing guilt. The result may be rejection, but often the relatives become overprotective

\*Committee on Sexual Problems of the Disabled (SPOD), 49 Victoria Street, London SW1.

with underlying feelings of hostility. This may be serious when a parent becomes overprotective, especially if the sufferer is married. A parent's guilt and anger may threaten the marriage. Other sufferers deny the disease so much that they refuse to acknowledge any limitations. Life then becomes difficult for all members of the family in a different way.

### Medication

Tranquillisers or antidepressants may be useful if the emotional difficulties of sufferers do not respond to counselling and if anxiety or depression becomes severe. A psychiatric opinion is necessary in some cases and a few patients will require intensive psychotherapy. When medication is prescribed it is important that the patient continues to receive counselling and that the medication is not regarded as an alternative treatment.

### Conclusion

The emotional and relationship problems associated with MS have not always been fully appreciated by the medical profession, which has tended to concentrate on the physical effects of this disease. Yet the psychological problems of MS often cause more suffering than the physical effects. We recommend that more attention should be paid to this aspect of the disease in terms of both clinical care and research. An example of what can be done is the Multiple Sclerosis Centre in Chicago, where the group counselling of patients with MS is part of a programme of comprehensive care.<sup>3</sup> We hope that counselling of MS sufferers will become standard practice both in the community and in hospitals.

### References

- <sup>1</sup> Burnfield, A, *British Medical Journal*, 1977, **1**, 435.
- <sup>2</sup> Surridge, D, *British Journal of Psychiatry*, 1969, **115**, 749.
- <sup>3</sup> Hartings, M F, Pavlou, M M, and Davis, F A, *Journal of Chronic Diseases*, 1976, **29**, 65.

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*Can chloramphenicol 0.5% eye drops produce gastrointestinal and other side effects?*

Ingestion of chloramphenicol can certainly cause gastrointestinal symptoms and rashes, and possibly in a sensitive patient eye drops may do the same. I would suggest changing to a different antibiotic if continued treatment is really necessary.

*Are there any recognised operations for lengthening the leg?*

Leg lengthening operations, because of their unpredictability, have to some extent fallen into disrepute and when possible it is preferable to shorten the other leg. There are, however, operations to lengthen the leg, mostly the tibia, in which the average lengthening amounts to about 2 in and the average time of union is about five months. The Achilles tendon is first lengthened and then the tibia is divided by a long oblique or step osteotomy, the fragments being fixed on an Abbot's type distraction frame by double fixed pins above and below the osteotomy. The limb is then lengthened by screw distraction at the rate of about one-eighth of an inch a day. When union is reasonably advanced the limb plus the pins are incorporated in a plaster cast. With the gradual distraction vascular and neurological complications are very few. Sepsis, however, has to be guarded against, particularly in the pin tracks. Any angulation of the fragments giving rise to pressure on the skin should be corrected early. The femur can be lengthened by an oblique osteotomy and insertion of an intramedullary nail that is not too tight in the medullary canal, and traction can be applied through a pin in the tibial tuberosity and increasing weights.