

number of elderly admissions, and an increase in their rate of turnover.

Unfortunately the increase in admissions of elderly persons to mental hospitals, and the improvement in turnover have not been matched by similar trends in the geriatric units. Here the amount of accommodation per head of population has fallen, the number of patients dealt with has declined, and the rate of turnover is lower. Though the mental hospitals may be seen as providing some relief for the geriatric problem, the extent of this relief is inadequate, and many would claim inappropriate. The new strains arising within the mental hospitals where staff are trained in psychiatric rather than geriatric care have already been mentioned. However useful as an expedient, it is no solution to the geriatric problem to admit more elderly patients to the emptying beds in the mental hospitals unless parts of these hospitals are radically re-equipped and appropriately staffed with persons properly trained for the change of duties. Kidd (1962) has written of "misplacement" of geriatric and psychiatric patients, and McKeown and Cross (1968) have produced broader evidence covering all hospitals and welfare homes in Birmingham.

The signs point to major difficulties ahead and the need for urgent reassessment of the scale of the geriatric services now required. At the end of 1967 there were 12 geriatric/chronic sick (staff allocated) beds for 1,000 persons aged 65 or over in the Birmingham region. If the lower level of provision recommended by the Ministry (10 beds per 1,000 aged 65 and over) is to be adopted for planning future accommodation, a dramatic rise in "productivity" as measured by turnover rates

must be achieved, and of this, although there are local exceptions (Parnell, 1968), there is no overall sign at present. The number of geriatric beds required may be debatable; they are expensive to build and at present not easy to staff; indeed, many are now staffed at levels below their current establishment, an establishment which itself falls short of the levels suggested by McKay and Ruck (1967) which a representative body of the British Medical Association has recently accepted as the national minima. However, there can be no doubt about the need for increased recruitment and training of both doctors and nurses in this field, if the most effective methods already available are to be put into practice. Failure will lead to progressive "blocking" of beds in hospitals for acute cases.

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## Motor Neurone Disease—a Patient's View

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"Do you think you could reorientate your thinking and change your way of life completely?" My reply to the doctor who asked me this question was that I thought I could, but only if I knew the extent to which I would have to do it. A series of investigations had led to a firm diagnosis of motor neurone disease. I am very glad that the doctor answered my questions fully and honestly, even to the point of telling me that I would need to be with people who were prepared to do everything for me. Being told that the disease was a progressive one enabled me to do things while I could and not leave them in the hope that I would soon be feeling better. For example, I had business and personal affairs to attend to and friends who lived a long way away I particularly wished to see, and it was very much a matter of going while I could get in a car and speak clearly enough to make myself understood.

In the 18 months between then and now I have felt a strong desire to share my thoughts and feelings in the hope that they will help doctors who have the difficult task of deciding how much they ought to tell any patient of theirs with the same disease. The obvious immediate answer is, "It will depend on the patient," but, since the disease does mean reorientation of thinking and a complete change in the patient's way of life, I feel that patients and their families should be told as much as possible in the home, in preference to the doctor's surgery or the rather tense atmosphere of an outpatient consulting room.

Doctors can help a great deal even though they might feel a sense of helplessness. They will be unable to help the patient

at all, however, unless they can help him to come to terms with the disease and accept it, and this, of course, involves the family, who initially will have the care of the patient. They can help considerably on their visits by asking simple questions requiring only "yes" or "no" for an answer and by sitting down facing the patient. I find it hard to talk to people towering above me, because of difficulty with neck control.

### Feeding and Sleeping Arrangements

General practitioners may be asked to advise those looking after motor-neurone patients at home on such matters as feeding and sleeping arrangements. On the matter of feeding, when it becomes difficult to cope with a solid diet, liquidized food is the answer. If a liquidizer is not available then tins of baby food can be used.

Eating gets increasingly tiring, and a plate with a base for hot water will help to keep the food hot. In extreme tiredness "milk foods" or meat extracts can provide nourishment and can be taken through a straw. It is important to remember not to attempt to hurry us. If choking occurs we should be given as much air as possible, sat upright, and patted firmly on the back until the tension has been eased and normal breathing restored. With regard to sleeping, the most comfortable mattress is the interior-spring type, and if a layer of foam rubber (minimum thickness 2 in. or 5 cm.) is placed between the mattress and the bottom sheet this will help to prevent bed sores.

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Ordinary blankets are too heavy; while a bed cradle can be used, the disadvantage is that if a muscle spasm occurs in the leg the leg will hit the cradle and get very bruised. Lightweight cellular blankets are preferable. These should be loosely tucked in in order to allow for freedom of movement. The room should be warm and airy.

The position of the head is most important and the neck needs to be thoroughly supported with a pillow underneath it. This must allow for the head to be turned quickly if it is necessary to get rid of an excessive amount of saliva. This usually occurs at the beginning of the night, but during the night catarrh tends to set in which makes breathing through the mouth necessary. This leads to a dry mouth, and a drink should therefore be readily available. A simple inhalant on a handkerchief on the pillow will help to clear the catarrh.

It is not perhaps realized that fear amounting to panic occurs by day or night, and it is therefore essential that help should be readily available, contact being made by means of a bell or buzzer which responds to the slightest touch. All need to understand that a change from adult independence to complete dependence is most frustrating and will lead to emotional changes such as sudden floods of tears or almost hysterical laughter which the patient cannot control. The main reason for not being able to stop is breathlessness, and normal breathing is best regained by the understanding shown by the relative or friend who is present when it happens. Once the tension has been eased the breathing will return to normal. Until the tension has passed the fighting for breath makes speaking impossible and the patient cannot say what is causing the distress.

### Speech Therapy

I think it would be a great help to patients with motor neurone disease if this matter of breathlessness could be dealt with at an early stage by help from a speech therapist or physiotherapist. I was fortunate in receiving advice on this from my speech therapist friend, who had been asked to call to see if she could help me improve my speech which was badly slurred. Breathing exercises combined with simple speech exercises have not only kept my speech understandable but have also helped me with my swallowing and enabled me to regain my breath following emotional distress. I am also indebted to my physiotherapist friends for showing me simple exercises which could also be done at home in bed or in the chair to keep the muscles moving and to stop the joints becoming fixed. For a time I did try occupational therapy at a local hospital, but this had to be abandoned because I found it too exacting—not so much the therapy itself but the strain of waiting, often for a long time, for hospital transport and then having out of courtesy to talk to the other patients in the outpatients' department, who naturally wanted to know what my trouble was, how long I had had it, and so on. I would therefore recommend that doctors with motor neurone patients should endeavour to organize home activity rather than hospital out-patient treatment.

An understanding of the unusual tiredness is very important. This illness calls for rest during the day and plenty of sleep at night. Doctors talk of "periods of remission," but the ability to do things fluctuates considerably from hour to hour. In discussing this problem with a young man suffering from the same disease he expressed concern that doctors were unable to give any advice on this particular aspect. My view is that only individual patients can sort this out. Over a period of

time I have come to recognize within myself waves of energy, which are followed by long periods of exhaustion. Things can be tackled while the energy lasts which should not be attempted once the exhaustion has set in.

### Public Ignorance of the Disease

If doctors can explain this to their patients and help them to recognize their flow of energy when it comes this will help them to lead a more varied life—for example, outings to the local cinema can be arranged, or visits to friends or short car drives. I think that it is important that motor-neurone patients, who are not ill in the ordinary sense of the term, should continue to feel part of normal society. This has its difficulties, because members of the public know practically nothing about the disease and associate slow speech and uncoordinated movements with mental deficiency. My young friend and I have both had experience of being thought mentally handicapped. We both found that, because when tired we had extra difficulty in speaking and therefore limited ourselves to words of one syllable, our listeners assumed that our education had not progressed beyond that stage, and therefore spoke to us in baby language. A student nurse asked me very kindly: "Were you ever normal?" I think she meant physically, but I have often wondered. . . .

We remain "normal"; the highly intelligent will continue to be highly intelligent and the inquiring mind will continue to be inquiring. Hearing also continues to be normal, and there is therefore no need for people to shout at us. One of the problems we experience is that we think but cannot express ourselves at the normal speed, and there is often a delay between thought and speech.

Is there any point in doctors encouraging their patients to fight a progressive disease? I thought originally that I would either have to accept or fight, but I came to the point where I was sure I could do both. I could accept the fact that I could do nothing to stop the advance of the disease, but that I should fight to stop the physical dominating the mental and spiritual. I knew I could do this only if other people were prepared to be my hands and feet and in that regard do everything for me.

My mother and brother looked after me at home for 10 months until I was in need of full-time nursing care. The loving kindness and understanding of my family, friends, and the Hospice staff has helped considerably to remove the frustration arising from physical limitations. The congenial environment has enabled me to express my personality and this has relieved the tension caused by the disease. I still feel the desire to be creative, and it has been interesting to see that other motor-neurone patients who prior to the disease were engaged in creative work feel the same urge.

With the practical help and prayers of others I have found it possible to set aside the physical and let the mental and spiritual take over. This is a very enriching experience.

I do hope that doctors will encourage their patients to lead as full a life as possible. I have often thought about St. Paul and St. Luke. Paul knew that Luke, the beloved physician, could not cure him because it was not part of God's plan for his life, but the help they gave to one another and to others by way of their friendship and companionship was immeasurable. Doctors of today should not feel that because they cannot cure motor-neurone patients they cannot help them. They can indeed help them by their compassionate understanding and friendship.