MEDICAL PRACTICE

Clinical Topics

Explanation and management of neurological disability

E M R CRITCHLEY, J D MITCHELL

Abstract

Patients are often told of the diagnosis of a neurological disability in less than ideal circumstances such that they may not fully comprehend it. Clinicians must be able to sense when the patient's understanding is imperfect even if superficially he or she appears to take in what has been said and its implications. A programme of further counselling is often required to follow this up. A critical look at current procedures will show how these problems arise. It is suggested that improvements in the care of neurologically disabled patients would follow from improved communication between the many agencies that are concerned in their care and from providing books and other material explaining disability and its treatment. A logical development would be for disabled living centres to be established adjacent to existing neuroscience units.

The initial diagnosis

Neurologists have repeatedly chided their colleagues, and perhaps themselves, for not giving a clear explanation of the implications of the diagnosis to many of their patients.^{1,2} The patient may not understand what has been said and there may even be difficulties in explaining the diagnosis. Just naming the disease and thus providing a label is clearly insufficient, and the public rightly expect more than this. A recent report has stated that "a frequent complaint is the inadequate information given to the disabled

person about the nature and the expected course of the underlying condition; about the treatment and the plan of management of the ensuing disabilities, and about the opportunities, services, and help that are available."³

An explanation of the diagnosis might be the culmination of the initial interview. But before the physician congratulates himself on his clinical acumen and plunges into an explanation he should consider whether the patient is receptive. One of the joys of neurology is the exercise of professional skill in adapting the questioning and examination to the ability of the patient to cooperate. Was the patient at ease going through a complex history? Were there lessons to be learnt from the patient's behaviour as well as clinical signs to be found during the physical examination? The assessment of the mental state encompasses an awareness of the degree of insight that the patient has into his condition. Is the slightly deaf patient lipreading or merely guessing? Dyspraxia, recognised during the examination of the motor system, may reflect poor comprehension rather than evidence of motor pathology. Sensory testing easily tires the patient and its subjectivity was emphasised to us all as students. In short, for a patient in a tense emotional state who does not know what to expect, the history taking and examination may be a prolonged, exhausting procedure that is made more difficult by a partial appreciation of what is happening.

At the beginning of the consultation the physician will have concentrated quite properly in getting as much information as possible from the patient to formulate at least a differential diagnosis. When giving an opinion and advice the patient's functional condition and reaction to the whole outpatient foray are additional factors for the physician to bear in mind. The patient is often handed an x ray or laboratory request card with appropriate directions at this point and then almost inevitably turns to the clinic nurse asking for the instructions to be repeated. This humbling event should remind the clinician that the patient either needs repeated reassurance or has difficulty in understanding what has been said.

Patients usually arrive for consultations armed with fears and

Department of Neurology, Royal Preston Hospital, Preston PR2 4HT

E M R CRITCHLEY, DM, FRCP, consultant neurologist
J D MITCHELL, MB, MRCP, consultant neurologist

Correspondence to: Dr Critchley.

presumptions about their illnesses and are rarely in a relaxed frame of mind. The vicissitudes of the transport system, ambulance services, and car parking do not add to their equanimity. The patient's uncertainties should be dispelled by the warmth of the staff and the professional rapport of the doctor. Economies which prevent a relative or friend accompanying the patient are false ones and mean that more time or even more appointments might be necessary to bring the referral to a satisfactory conclusion. Even if the "main helper" suffers from a serious handicap,⁴ his or her presence is stabilising and reassuring to the patient. The escort may be better prepared than the patient to appreciate and discuss the explanations given and can repeat what has been said later when the patient will hopefully be more relaxed. At least the escort can say that the patient can discuss things with his family doctor when he has received a letter from the consultant in a few days. The wisdom of a second member of staff adding more than a word of reassurance as the patient leaves the clinic is dubious as this may emphasise the fact that the patient has not yet composed his thoughts and thus merely obfuscate the situation.

The outcome of the initial consultation may be a clear diagnosis, reinforced by discussion with a relative. Alternatively the diagnosis may be uncertain and depend on further investigation of the patient either as an inpatient or as an outpatient. It is also possible that the diagnosis may be abundantly clear to the physician but that for one reason or another the time is not opportune for detailed explanations and discussions. These points are perhaps better considered by looking at specific examples.

Motor neurone disease

The physical examination may leave little doubt as to the diagnosis of motor neurone disease, but the implications are such that it is reasonable to admit the patient for full investigation both to allow the exclusion of any other process that might be potentially treatable however unlikely this may be and to permit detailed discussions with the patient and relatives. This does not preclude the patient being given some indication that he has a potentially progressive muscle wasting disease resulting from a disorder of the nerves at the initial consultation. Once the diagnosis is established beyond doubt there must be full discussion with the relatives regarding the prognosis and eventual outcome. Absence of intellectual and sphincter involvement should be emphasised as well as the fact that the skin tends not to break down over the pressure areas in this condition. If the patient asks if the condition is potentially lethal the answer must in almost every case be 'yes'. If the reply to this question is ever given in the negative, this is manifestly false information. None the less this is often done with the best intention of shielding the patient from the grim truth. Few patients really accept this, particularly as they see themselves steadily deteriorating, and will usually find out the true state of affairs even if this means going or sending someone to the public library. Once this has happened there is likely to be an instantaneous breakdown of any trust which had previously existed between patient and doctor.

Follow up consultations are necessary to assess the need for further appliances, speech therapy, communication aids, or even cricopharyngeal sphincterotomy in selected cases. Hospital visits may eventually overtax the patient and consideration should be given to obtaining domiciliary assessments. Postural drainage should be taught and the advisers of the Motor Neurone Disease Association are of great help in discussing what can be done in the home to help the patient and relatives cope with the disease and to make full use of the provisions which are available from many sources.

Multiple sclerosis

Despite wide ranging research into the underlying cause of multiple sclerosis a "diagnostic" test is not yet available. The final diagnosis must still be made on clinical grounds, and many years may elapse from the first symptoms until this is possible. Even if the diagnosis is communicated to patients at this stage there may be considerable difficulty in understanding why they have not been told before for they may have long suspected that this is their diagnosis. This having been said, it is clear that the doctor must be satisfied in his own mind of the diagnosis of multiple sclerosis before discussing its implications with the patient and it is important that the general practitioner is informed when this has been done. Undue delay will only lead to serious difficulties with the longer term management, and the

patients will inevitably have assumed the worst possible connotations that they will become bedridden and wheelchair bound at an early age.

Thousands of people have multiple sclerosis and continue in gainful employment with reasonable mobility for many years. Others can lead a remarkably full life, despite a degree of handicap, and it must always be remembered that dramatic improvements can sometimes occur. Knowing the diagnosis is an essential first step to the constructive discussion of measures such as special diets, which are from time to time suggested as being of benefit. An informed patient is better able to adjust to pregnancy, sexual difficulties, incontinence, or even depression and feels free to bring up specific problems as they arise.

Epilepsy

The diagnosis of epilepsy depends on the description of a series of ephemeral events by the patient or a witness. Amplification of the history and investigation does not confirm the diagnosis in every case but from the medicolegal standpoint an unexplained episode of loss of consciousness is regarded as though it were epileptic. It is therefore necessary to stop patients from driving motor vehicles despite uncertainties until a more authoritative pronouncement can be made. In this way attacks lasting but a few minutes may become a disability of lifelong importance, a fact of which the public is all too aware. Counselling is therefore needed at an early stage to prevent unnecessary stigmatisation. Epilepsy is a symptom, not a pharmacological exercise in which serum anticonvulsant concentrations are monitored as though they were blood glucose concentrations.

The treatment required is that which will prevent attacks. The patient expects to know the aetiological diagnosis as far as possible. Possible trigger factors that may break through medication must be explored and the effect of the condition on the patient's lifestyle, occupation, social activities, and drinking habits discussed. Continuation of this approach at follow up may encourage compliance with treatment. If either marriage or pregnancy is contemplated a discussion with fiancée or partner may help to allay fears of possible genetic implications.

Head injury

Although head injury is not the only cause of neurological disability affecting young people, the economic sequelae of head injury are far reaching. The victim is often the provider for a young wife and family, and the effects of the injury often mean that the burden of care falls on those who might have been able to provide an income in default of the injured person. The economic consequences of this are obvious. Much effort has gone into educating the public regarding road safety in recent years. This, coupled with the introduction of seat belt and crash helmet legislation, has led to a reduction in the number of road traffic accident victims with severe head injuries. Despite this, however, accidents still occur and motorcyclists in particular remain at considerable risk of sustaining head injuries.

Intensive care is required in the acute stage of severe head injury, and head injured patients are therefore usually managed in either a general or a neurological surgery unit. Local arrangements vary widely and the ideal has been the subject of much discussion. Undoubtedly many lives are saved in the early stages by the prevention of secondary complications, but a surgical environment rapidly becomes less than ideal as the recovery phase progresses. An acute general surgical ward is not the best place for any head injured patient requiring active rehabilitation. The physical sequelae may be blatant in cases of major head injury. There may also be more subtle changes, particularly when the injury has been less severe. In broad terms, these less obvious changes tend to have psychological implications. Those with frontal lobe damage may show profound behavioural changes: parietal lesions may also impair full rehabilitation. Patients may have problems with learning, language, and memory. Emotional difficulties, sometimes with troublesome mood swings, are also often a feature. Active physiotherapy and occupational therapy are crucial in the management of physical disability. The speech therapist also has an important role in the treatment of those with communication problems. An experienced clinical psychologist is probably the key person in the treatment of frontal lobe damaged patients with the major behavioural difficulties which are often the main barrier to successful rehabilitation.

The need for patients with head injury to be treated in an appropriate environment will therefore be clear. This is not a setting where the efforts of the staff are concentrated on saving the lives of acutely ill patients. There must be therapists definitively attached to the unit as well as an active psychological input. Psychiatric help must be readily available. The important contribution of voluntary organisations such as Headway should also be remembered. It is unlikely that separate units for the rehabilitation of head injured patients attached to all neuroscience units would be entertained

in the current economic climate, but there seems to be a clear case for the establishment of units with a special interest in this aspect of rehabilitation at least on a regional basis.

Causes of failure

Although most clinical colleagues are skilled at the art of presenting their initial diagnosis, this is too often inadequately followed up and the patient is left isolated with the comfort or otherwise of a diagnostic label. Unless there is a programme of investigations brought together by a return appointment, the outcome of the initial consultation depends heavily on the consultant's letter to the general practitioner. The outpatient sister cannot coordinate support in the same way as the ward sister, who is often a key figure in liaison with paramedical services. The ward sister can contact therapists and help to arrange aids and appliances. She can also make a link, through the health centre, with district nurses and other community services. Each of these has to be specifically arranged from the outpatient department. The consultant can also arrange hospital services, but the value of physiotherapy and occupational therapy has to be balanced against time spent travelling or waiting for transport. General practitioners can request the involvement of health visitors, home helps, social services, and domiciliary physiotherapy where available. A proper home assessment to adapt the home to the needs of the disabled person requires the cooperation of housing authorities, social services, and occupational therapists under the guidance of someone who can organise an overall plan looking beyond what is available from his own department.

Under the Chronically Sick and Disabled Persons Act 1970, local authorities have an obligation to inform themselves of the number of disabled people in their district and to take steps to meet their needs. In pursuit of the requirements of this act there should be a system of notification, a dependency register, and a monitoring system. In the present climate notification of disease acquired in adult life is regarded as an invasion of privacy. Attempts to provide a comprehensive handicap and crisis service coordinated by a district disability team linked to voluntary services are frustrated due to lack of information. The circumstances of the disabled person can alter rapidly after marital breakdown, progression of disease, and illness or death of the main helper. A formula allowing the notification and regular assessment of the state of all disabled people while respecting their need for privacy is urgently required.

Improvement in management

Patients have a right to know and those with a disability have a need to understand almost as much about their individual condition as the doctor advising them. This has long been the dictum for diabetics. A patient with Parkinson's disease who has reached the stage of reduced drug tolerance should be encouraged to experiment in the flexible manipulation of his drugs under the guidance of his medical advisers to achieve the maximum therapeutic benefit. Too often the provision of a Possum apparatus is considered too late in the illness so that the proper advantage cannot be made of it. This also applies, perhaps to a lesser extent, to other aids. There is also often an unsatisfactory delay in the supply of articles after they have been requested by the clinician or therapist. Until such problems can be overcome an element of anticipation is therefore required. To ensure the provision of such appliances at an optimal stage one might speak in terms of a "safety net" in case the "worst should come to the worst" when first discussing them with the patient in the hope of avoiding undue demoralisation.

There are other aspects of management that apply to all disabled people. These include records of drug and other treatments, which provide a rapidly accessible and easily assimilated review of what has been previously done, thus saving unnecessary

duplication of effort. It is helpful to record a patient's known drug allergies, sensitivities to drugs taken in normal dosage, abnormal psychological or other reactions to drugs, any genetic disease, and any kidney, heart, chest, or liver disease that might affect the distribution and elimination of the drug. The patient could be issued with a card detailing the drugs taken and dosage regimen along with precautions to be taken by the patient and an outline of any symptoms which may herald side effects. This is already done to an abbreviated extent by some pharmacists, but clearly only a limited amount of information can be carried on container labels, and a card could include a space where the patients could list details of possible side effects that they have noticed themselves.

This approach might be extended to facilitate follow up consultations. Diary cards and a list of current drugs considerably streamline the review of patients with epilepsy and migraine. Patients should not only be given clear instructions as to what to do if problems develop but perhaps more importantly told what to do if the health centre receptionist suggests an appointment the following week. Drug regimens should be tailored to diurnal fluctuations in disability. This is particularly important in many patients with Parkinson's disease. It is possible that research by non-disabled workers may not suffice and that the desirability of peer group studies into the needs of other disabled persons should be considered—for example, tetraplegic patients trained in psychology interviewing fellow sufferers.

The National Health Service has been slow to recognise the value and availability of the excellent guidebooks that have been written for patients and their relatives on living with a wide range of disabilities and diseases. Most of these are well written and up to date and provide an honest yet sympathetic account of the disease they describe. They explain the problems that can arise and what can be done to help. The listing of agencies which can help by advising on appliances or supported holidays is particularly useful. With the current retail activities in hospitals, perhaps such works should be on sale alongside the refreshments in outpatient departments.

The report on "Physical disability in 1986 and beyond" by the Royal College of Physicians proposes a series of reforms to improve the management of the disabled. One of the most exciting is the proposal that disabled living centres should be established. These would have two principal functions: (i) to provide a permanent standing exhibition of a range of aids and equipment with a supporting information service and (ii) to act as an education centre for staff, volunteers, and patients. Such a centre would occupy rooms "the size of one or two standard hospital wards" and would bring together voluntary, NHS, and social services. Referral would be encouraged from any source, including self referral by disabled people. With 60% of disabled people having a neurological diagnosis, it would be logical for such centres to be developed adjacent to the outpatient clinics of neuroscience units. Neurologists should encourage the therapists in charge of disabled living centres to exhibit posters and pamphlets from the associations concerned with the needs of the physically handicapped and to generate competition in the provision of more efficient and up to date aids than are at present available, such as improved splintage devices and more practical wheelchairs.

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