Living with stroke

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Introduction

The number of those in the community who have suffered a stroke leaving them with permanent disability is not truly known. Strokes vary in severity from those which leave the patient obviously and severely affected by such profound disabilities as hemiplegia and aphasia, to those which cause such minimal damage as to have escaped casual notice altogether. As one of the major consequences of that commonest of pathologies, cerebral atherosclerosis, the count must be in the many tens of thousands; since vascular disorders increase with advancing age, so it is reasonable to assume that the total number of those surviving strokes is increasing daily within our society.

So what is it like to live with a stroke? The author's experience derives from interviews and examinations conducted in the homes of nearly 200 patients so diagnosed. The individuals concerned without exception had been hospitalized following their strokes and therefore represent the more severe stroke sufferers. Although the study concentrated on the younger section of patients, namely those under 65 years of age, the great majority of those previously at work had retired. Many had been forced to this position as a result of their sudden impairment. Others had merely stopped work a year or two earlier than would otherwise have been the case, because, bearing their health in mind they had reconsidered the relative value to themselves of work and leisure. Some blamed pressure of work for their stroke in the first place. Nothing reminds an individual of his own mortality more forcibly than an acute catastrophe like a myocardial infarction or a stroke.

The early days

The immediate experience of those affected is the stroke itself, sometimes unremembered, the ambulance journey to hospital and the weeks spent there before discharge home. During that time the majority

of those who survive recover to a greater or lesser extent, although nearly all are left measurably impaired, for example with weaker limbs or diminished intellect. As improvement slows or appears to stop altogether, so discharge dates are set and the patient returns to his family.

In hospital the emphasis is almost entirely on useful recovery of physical ability. The aim of a complete return to normal stands before every patient. As recovery often occurs relatively rapidly at first, so the goal seems attainable, but then it slows down and uncertainties arise as to the final picture. To most patients the physiotherapist holds the key to recovery. There is, after all, no other apparent 'treatment' offered. Therefore the more determined and energetic the exercise the greater and more complete is the prospect of ultimate recovery perceived. This is the inescapable and uncontradicted initial conclusion of the majority of patients. Discharge from hospital and discontinuation of physiotherapy may bring the first realization that treatment is finished. Thus continuing physiotherapy at home is the exception rather than the rule. Arriving home also leads to further disillusionment in some patients. In hospital one is expected to be disabled. At home the reality of that disability becomes painfully clear when the hospital's assessment of motor dysfunction is translated into an inability to go upstairs to bed or get into the bath without assistance from one's spouse. For those who previously were breadwinners, there is the further painful realization that this prestigious position is lost and, to make matters worse, replaced by a dependence on others.

These observations suggest an uniformity of response to the occurrence of a stroke. Such, of course, is not the case. Patients differ from one another in a number of ways, personality, social circumstances, previous health and the nature of the stroke itself being amongst the most important of these. The occurrence of depression and its severity and duration also profoundly influences outcome.

Strokes, like head injuries, call upon the ability of

the individual to adapt to sudden change. This ability varies and not surprisingly those who have demonstrated adaptability in their lives before tend to do better than rigid, obsessional individuals whose inability to compromise, and single-minded determination to achieve complete recovery, not infrequently leads to depression and despair when total success is not achieved. Those without this drive usually settle more resignedly for a less self-sufficient life. Those whose personalities are marked by traits of dependence find in their new role a fresh justification for leaning on others. To complicate evaluation in this area, in assessing what is often referred to as motivation it is important to remember that brain damage itself alters the individual's ability to behave adaptively so that previous ability to cope realistically and determination now to do so may not be enough.

After the first year

A frequent finding at interview, a year or more after a stroke, is the presence of irritability which may amount to aggressiveness and a self-centredness which makes living with such a person a burden for the family or those in a caring role. For some, unfortunately, the situation is intolerable and they seek separation or divorce. Such alteration in personality may be obvious to the casual observer but more often such changes are apparent only to those who have known the patient for years. Other commonly reported changes are that the patient has become more worrying in disposition, less energetic and less outgoing. More welcome is the occasional report of an 'improvement' in personality, manifested by greater care and consideration for others, less anxiety and less aggression. Some do report that the patient is easier to live with after his stroke *than* he was before it. The majority of patients, on the other hand, appear to be unaware or only partially aware of such changes in themselves. It is of paramount importance to realize that from the family's point of view such factors may cause far greater problems and distress than the difficulties and problems posed by the physical side of care.

Those with greater pre-morbid resources in terms of interests do better than those whose only interest was their work. They have more to fall back on when they are forced to retire, particularly if those interests make little demand on physical ability. Those who valued highly their physical prowess clearly suffer a more severe loss than those of a sedentary nature. Those who previously spent much time watching television can go on doing so with little change in life-style.

Social factors play a crucial part in the quality of life of those surviving a stroke. Those with enterpris-

ing spouses who make determined but realistic demands of the patient do better in terms of eventual self-sufficiency than those whose partners allow them to slip into apathy and inactivity. Clearly those who can afford a comfortable life-style, perhaps with holidays abroad and domestic help, appear to be more satisfied than those who live in relative poverty with no means of brightening monotonous lives. For those who feel more secure and less anxious in the sick role and who are married to spouses who welcome the opportunity to assume a totally caring role, a kind of success is achieved. Not surprisingly such families prove very resistant to attempts to bring about change.

Thus the quality of life in the home, which is the arena for the great majority of stroke patients, depends critically on the provision of adequate income, a range of services and diversionary activities.

Facilities available

Unfortunately, the extent and quality of this provision varies widely and although by comparison with undeveloped countries we are fortunate, much remains to be done. Services vary from one part of the country to another and although middle-class patients generally fare better than working-class patients because of their greater self-reliance, enterprise and initiative, most families are unaware of mobility and attendance allowances, ignorant of the existence of Stroke Clubs and uncertain how to get into a Day Centre. They do not know how to go about arranging meals-on-wheels or a home help, nor who qualifies for visits by a district nurse. They may have problems getting such aids as special rails for a bathroom, without which a difficult life can become an intolerable one. Such matters should properly be explored while the patient is in hospital, mediated by Social Services and followed up in the community. In practice this provision is often at best partial through lack of resources, failure of organization or reluctance on the part of the patient or family to accept plans that appear to confirm the patient's helplessness and irreversible dependence. The situation could be improved by tightening existing arrangements and lines of communication, by greater mobilization of voluntary services essential to cope with growing demand, and by better preparation of people in general for retirement, infirmity and old age.

The patient's disabilities

The patient's previous health is another factor powerfully influencing the quality of life in those surviving a stroke. Many patients have cerebral atherosclerosis, with or without hypertension, and carry the stigmata of this before their nominated

cerebro-vascular accident. They may have had one or more strokes previously, with focal signs already evident. The informant's account may reveal a history of increasing cognitive impairment, memory loss, alteration in personality and change in mood, to which are now added the further changes brought about by the stroke in question. In the same way those with the multiple pathology that is so common in later years will be worse off than those who had previously escaped the ravages of arthritis, chronic lung disease and failing eyesight.

The common syndromes of stroke are well known and represent a wide spectrum of organic impairment. What it is like to live with a stroke will clearly depend on the nature and severity of the symptoms which in turn will depend on the site and extent of the pathology and its rate of progression. At its worst it may lead to profound disturbance of movement and co-ordination, perceptual anomalies, intellectual inaccessibility and loss of speech and comprehension. At the other extremes there may be minimal uncoordination or barely detectable weakness of a limb. The author was certainly surprised to find, when following up patients a year or more post-stroke, how few were seriously disabled or severely demented. Many were able to carry out most or all activities of daily living. It would be true to say however, that to the extent that outcome can be quantified, mental exceeds physical disability.

There are a number of features of stroke illnesses that may not be readily apparent but often cause disproportionate distress to the sufferer. Included amongst these are the rigidity of set which makes moving from one subject to another fluently such a problem for those with brain damage; the homonymous hemianopia, sometimes only an attention defect, which makes crossing the road so dangerous and which is only discoverable on careful testing of the visual fields; the apraxias and agnosias of parietal lobe damage which may not be recognized and the visuo-spatial disturbance which may make simply crossing a room a perplexing and frightening experience. All these may make the observer believe the patient is simply not trying. Patients with aphasia of all types complained often that on the one hand they were able to understand what was said and be distressed by it sooner than people realized and on the other, usually at a later stage of recovery, they were not given sufficient time to make a reply. Those with dominant hemisphere lesions causing slight difficulty with communication say this difficulty is often not appreciated at all by friends and relatives.

Depression of mood is almost universal after strokes, as it is after any acute catastrophe. Only those so severely brain-damaged as to be demented and left completely without insight are saved from this particular sequel. With the passage of time

allowing a measure of clinical improvement in the stroke deficit pathology, and a degree of adaptation, this response becomes less common and only about a quarter of all patients were found to be significantly depressed one year after their stroke. Such depressive illness is more common in those who have previously shown a propensity for responding in this way to adversity and in those with a family history of affective disorders. It consists not only of depressed mood and hopelessness but also loss of appetite and weight, poor sleep with early morning waking and diurnal variation of mood, over-emphatic somatic complaints, agitation or retardation, and other symptoms of the depressive syndrome whose significance is often lost on those dealing with such patients. Too frequently these symptoms are not noticed, their meaning is not appreciated, or, if depressive illness is diagnosed, it is considered inevitable and untreatable. In fact a therapeutic trial of antidepressants is imperative. Care must be taken, especially with elderly patients, but with an adequate dosage for at least a month, warning of possible unwanted effects of the drug and a reminder of the delayed onset of effectiveness of the antidepressants, there is every hope of a satisfactory outcome. Electro-convulsive therapy is not contra-indicated.

It may be concluded therefore, that for many stroke victims all aspects of life, physical and mental, are altered as a result of the 'accident' that occurred. It would be mistaken to pretend that even with the best care and every support, the lives of some patients are not permanently made less rewarding. However unrealistic it may be, many will settle for nothing less than a whole body and a whole mind. The aim of intervention is to help the patient and family derive the greatest possible satisfaction from the life that remains. This process should start with the stroke itself and end with the death of the patient and the grief of those that remain. It should merge imperceptibly into the care of the elderly that should be an integral part of the proper functioning of a caring society.

Making the most of a bad job—do we do enough?

At present there is usually too sudden a change from hospital management to the position the patient finds himself in at home. How well prepared are stroke patients and their families for the future? In my experience, with some exceptions, not very well at all. As with the care of the terminally ill, those with this potential task seem often to avoid it. Strokes seem to present an embarrassing defeat for doctors, nurses and others conditioned to expect their interventions to lead to recovery. Much attention is paid to physiotherapy and other physical aspects of treatment. Important as these are for certain aspects

of management, it seems almost as though this busy preoccupation endlessly puts off the need for direct confrontation and explanation that the stroke may well lead to permanent loss of function, permanent inability to do some of those things the patient did before and permanent need for help with independent activities previously taken for granted.

In practice, questions about the future are sometimes turned aside with bland reassurance and encouragement to try harder. Little or no information is volunteered and the ignorance of patients and their relatives is apparent when they are questioned at home months after the stroke. The most common fear is that there will be another stroke, though this possibility has usually not been discussed. Those measures which might favourably influence the prognosis—loss of excess weight, discontinuation of smoking and careful monitoring and treatment of hypertension—are rarely known by the patients or their families. Several patients on follow-up were discovered to have dangerously high blood pressure. Perhaps what is most disturbing is that the emphasis on exercise as an apparent method of improving physical performance and instilling life in paralysed muscles is perpetuated outside hospital in thousands of homes where stroke sufferers continue to flex weakened or plegic limbs in the clear expectation that this will one day bring about recovery. Saddest of all, these patients were never told or shown that there are many activities still open to them, that they still have a 'good' arm, that their hearing is unaffected and so on. Days that could be spent making the best of what remains are spent instead making the worst of what is lost. This is not to minimize the significance of the residual deficits, but to maximize the desirability for all individuals, whether they have experienced a stroke or not, to make the most of such assets as they have, physical and mental. Patients may well need help to come to terms with the loss they have experienced, but if the loss is not even acknowledged how can constructive help be offered?

Of course it is true that many recover to a remarkable extent and it is sensible to wait for a few weeks before making what may otherwise prove to be misguidedly pessimistic predictions. The state of the individual before leaving hospital, however, is usually a good guide to what can be expected in the end. At the least such matters could be discussed at this time with the spouse. Hopelessly unrealistic expecta-

tions could be dispelled avoiding unnecessary disappointment and the positive aspects of life with a stroke could be stressed.

Even those without a medical training can understand a simple explanation of what happens when a stroke occurs, how oedema initially worsens the physical picture, how its gradual resolution leads to improvement with recovery of function and how skilled and enthusiastic rehabilitation can lead to further functional benefits over months or years. They can also understand that the eventual extent of permanent brain damage is a matter of fortune.

It is a sad irony that in common with terminal disorders, although most doctors prefer not to be too explicit, most patients would like to have been told more, without removing the hope that things may continue to get better. The proper question is 'What does the patient know and what does he want to know?' Discussions at intervals with patient and family, including allowing them to tell us what is in their minds, are essential in order to establish rapport and confidence by them in the professional team. This can be pursued after discharge from hospital. With such close contact there is every chance that the right things will be said and done at the right time.

Conclusion

Perhaps the best way to understand what living with a stroke is like is to read the accounts of those with first hand experience. 'When the stroke struck me—at the age of 50—my life became incomprehensible. Nobody would tell me—or I would not let them tell me—what was the matter with me. And when they did—or I would let them—my life was one of blank despair. Now at the age of 60, I am healthy and independent (with the exception of my tendency to tennis elbow!) And in recent years, my life has been full of surprises, full of excitement, and full of satisfaction.' So Douglas Ritchie ends his book *Stroke*. It is the diary of partial recovery of a man who knows what it is like to live with a stroke, because he had one.

Bibliography

- RICHARDSON, A. (1959) *Never Say Die*. Max Parrish, London.
 RITCHIE, D. (1960) *Stroke*. Faber and Faber, London.
 WINT, G. (1965) *The Third Killer*. Chatto and Windus, London.