

AN EVALUATION OF HOME CARE AFTER SPINAL CORD INJURY

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THE ultimate objective for nearly every patient with a spinal cord injury is to return home and if possible to play a positive role in the community.

From the time of admission, the function of the social worker, together with other members of the hospital team, is to help the patient towards this goal and to achieve a life as near as possible to what it was *before* disablement. Successful return home depends in the first instance upon the cooperation of the patient and a stable family background. Suitable accommodation and supply of equipment must be provided and the services of the general practitioner and district nurse organised where necessary. Transport should be made available and possibilities of employment be investigated. The help of voluntary organisations may also be needed.

In an endeavour to find out whether or not the arrangements made for home care are adequate I followed up those patients admitted to the National Spinal Injuries Centre in 1972. This year was chosen as the most recent from which results could be evaluated. Of the 198 consecutive patients admitted in that year, 73 were excluded for the reasons shown in Table I.

TABLE I

Exclusions from survey

Died	4
Private patients	25
Members of H.M. Forces	11
Transferred to original hospital of admission	13
Transferred to units for the young chronic sick	6
Remain as in-patients at Stoke Mandeville	5
Returned home without assistance	9

Total	73

This left a total of 125 who were discharged and required home care. All were substantially disabled though some were incomplete lesions. Of these, 89 were paraplegics and 36 were tetraplegics as shown in Table II.

Arrangements for discharge were made by me for 108, all of whom I knew personally, whilst the remaining 17 were helped by a colleague. All had been followed up routinely after discharge.

To obtain further details for this paper, questionnaires were sent to each of the 125 patients, of which 110 were completed. The returned questionnaires were often accompanied by letters containing additional information. The results of the questionnaires are shown in Tables III and IV.

TABLE II

	Paraplegic	Tetraplegic	Total
Men	66	24	90
Women	16	12	28
Children	7	0	7
Total	89	36	125

TABLE III

Services used by 110 patients	Percentage of patients using each service	
	Paraplegic (81)	Tetraplegic (29)
Re-housed	35.2	36.1
Extension	18.9	11.1
Adaptations	63.5	66.7
Completed before discharge	50.0	40.0
Completed after discharge	50.0	60.0
Home nursing equipment	60.8	100.0
Special facilities	16.2	55.6

From the figures shown it would appear that all the patients followed up were provided with suitable accommodation. This is not in fact so. Some of the 110 are shown under both headings of re-housing and adaptations. Three patients, all living in overcrowded London boroughs, still await re-housing. Seven patients have still not had any alterations done to their houses. Fifty-five per cent of housing problems were not resolved until *after* discharge and this is attributable to:

- (i) lack of cooperation or change of circumstances on the part of the patient and family;
- (ii) local authority procedures and shortage of money;
- (iii) difficulty in getting builders—as many as 30 builders may have to be approached before adaptations etc. can be undertaken;
- (iv) resolving the family situation—many Social Services departments are wary of following a course of action when there is the possibility of a breakdown of a marriage or uncertainty about a young disabled person remaining at home.

Home nursing equipment was readily available and provided free of charge in almost every case.

A far higher percentage of tetraplegics were supplied with special facilities such as the installation of an environmental control, telephone, typewriter, services of a home help, etc., for obvious reasons.

The services and goodwill of the general practitioner and district nurse are

TABLE IV

Services used by 110 patients	Percentage of patients using each service	
	Paraplegic (81)	Tetraplegic (29)
Own doctor	70.3	83.4
District nurse	33.8	72.2
Health visitor	17.6	22.2
Social worker	59.5	72.2
Disablement resettlement officer	33.8	30.6

TABLE V

100 Patients	Paraplegic		Tetraplegic	
	Male	Female	Male	Female
Employed	19	1	2	1
Seeking Employment	3	0	1	0
Unemployed	24	1	9	4
Awaiting re-training	5	0	1	0
Full time education—under 26	5	5	4	0
Married women running their own homes	—	11	—	4
Total	56	18	17	9

vital and it can be seen from Table IV that they were used extensively—particularly by the tetraplegics—especially in the management of bladder, bowels and skin. Many patients were seen by their own doctor once a month or even more frequently. The district nurse, in the case of tetraplegics, often attended three or four times a week and in some cases daily.

The health visitor was involved usually only where there were young children in the family so the percentage of visits made overall was low.

The Social Worker showed a greater interest in the tetraplegics than the paraplegics, whilst the Disablement Resettlement Officer was almost equally concerned with both, through employment for tetraplegics is necessarily limited.

Employment could be considered as an index of the success of home care. Only 100 of the questionnaires returned answered questions about employment. Table V shows the results.

Of the 19 male paraplegics fully employed six are professional men who returned to their previous jobs as physicist, palaeontologist, architect, nutritionist, teacher and civil engineer. Of the remainder two are switchboard operators, two are draughtsmen, one is a metal engraver and eight are in clerical posts. Both male tetraplegics have administrative jobs and the one female tetraplegic working is a teacher.

The three men seeking employment all live in rural areas and in one case approaches have been made to 15 firms without success. Over one-third are unemployed. This is due to:

- (i) medical problems and old age;
- (ii) absence of job motivation;
- (iii) over-protective attitude of family;
- (iv) state benefits being frequently higher than earning capacity;
- (v) awaiting compensation;
- (vi) difficulties with transport.

Of the 100, only 19 men and four women have their own cars converted to hand controls. Invacars are used by 11 men and two women. It is known that the young, particularly, dislike Invacars as they feel that it labels them 'cripple'.

The sum of 14 people in full-time education consists of seven children under the age of 16 attending special schools. Two young men are up at Oxford. One of these is a tetraplegic who is maintained in rooms in college by the fullest social services being made available to him 24 hours of each day. Two other male tetraplegics have home tuition for General Certificate of Education 'A' Levels and a paraplegic male is studying for the same exams at an ordinary school. One female paraplegic and one male tetraplegic are at a residential college of education.

The four tetraplegic married women all run their own households with some assistance and one in particular is very active. She also cares for five children. Eleven paraplegic married women are occupied with the care of their families and homes. One of these has recently had a baby and one of them does a job as well as being a housewife.

Two points of interest emerge from this survey. Firstly, the resulting data indicates successful rehabilitation and that *services* for home care are more than adequate in the majority of cases. However, secondly, from the letters received and additional comments on many of the questionnaires, there is a strong suggestion that home care still leaves *much* to be desired. A sense of humiliation, resentment, anger and frustration was expressed by many patients. A lot of the bitterness was directed against the Social Services Departments and I quote from three patients:

- (i) 'I feel I should make clear the kindness and good intentions of all the welfare people concerned. For the benefit of future disabled persons I must make equally clear their deplorable ignorance of their own job';
- (ii) 'The Social Worker seems to be the weakest link in the National Health Service';
- (iii) 'I dare not commit to paper *what* I think about the Social Services'.

My conclusions are, that in spite of suitable housing and social services being available to patients returning home after spinal cord injury, only a minority play their optimum role in the community.

The patients seem to divide sharply into two groups. Those who succeed despite enormous difficulties and those who are not able to withstand the pressures of severe disability and often end up disillusioned and resentful. It seems to me that the problem is to find the factors which may well be missing in the transitional stage between hospital and home.

I would like to suggest four possible factors which may be important at this time:

1. Communication with the patient's family doctor.
2. Greater continuity in working with and seeing the patient's family throughout and particularly at the end of his stay in hospital.
3. Domiciliary visits by hospital staff both before and after return home to provide some continuity and to keep confidence high.
4. Distribution of information about services available to the patient.

My further comments on these points are:

1. The family doctor should be aware of a patient's admission to hospital so that he can be involved with the patient and his family throughout. This contact is of particular value when a patient goes home for periodic visits during his stay in hospital.
2. Families are seen often when a patient is first admitted. Thereafter, they tend to visit mostly at weekends, when a social worker is not usually available. The main responsibility for contact with the family therefore lies with the Social Services departments, whose social workers often have little or no experience of spinal cord injury.
3. Many of the problems encountered by spinal cord injury patients could be overcome if domiciliary visits were made by members of the hospital teams prior to discharge and after. The value of such contact is stressed by Meine (1970) and Francis-Jones (1972).

A major difficulty exists with regard to the above. The catchment area for the National Spinal Injuries Centre is the world! The distances and time involved usually precludes many domiciliary visits being made. Of the 110 patients reviewed 60 per cent live between 30 and 100 miles away from Stoke Mandeville, 28 per cent over 100 miles and only the remaining 12 per cent within a radius of 30 miles.

4. Information about the many facilities for the disabled and how to use them should be made available in printed form if possible. The newly formed Spinal Injuries Association is happily beginning to assist in this matter.

I believe that if the above suggestions could be put fully into effect, and if Social Workers outside hospital and Disablement Resettlement Officers were to receive more specialised training, then more patients could achieve greater independence at home and reintegration into the community.

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