ABC of Spinal Cord Injury

ERICA BAMFORD
DAVID GRUNDY
JOHN RUSSELL

SOCIAL NEEDS OF THE PATIENT AND HIS FAMILY

Where patients are living

	%
Living with relatives after discharge	79
Living independently after discharge	14
Living long term in residential care after discharge	0
Required interim residential care on discharge	9
Transferred to other hospital	9

Some patients appear in more than one category.
Figures derived from new injury discharges from Duke of Cornwall Spinal Treatment Centre in 1984-5.

The aim of successful rehabilitation is to enable the patient to live as satisfactory and fulfilling a life as possible. This will mean different choices and decisions for each individual depending on the degree of disability, the family and social environment, and preferred lifestyle.

The vast majority of patients want to live in their own homes and not in residential care, and even very severely disabled people can often successfully achieve this. Many will live as part of a family, but, increasingly, disabled people are choosing to live independently with support from community services. This presents a considerable challenge to these services.

For most people spinal cord injury demands changes in almost every aspect of life—personal relationships, the physical structure of the home, work and education, social and leisure pursuits, and financial management. Consequently exhaustive and careful planning by the spinal unit staff, and staff responsible for community services, in conjunction with the patient and family, is essential. Because of the complexities and scale of what is required, this planning should start as soon after injury as possible. PredischARGE planning is only the start of a lifelong, probably fluctuating, need for services. In providing these the social and emotional well being of the person and family must be considered along with physical health. Physical health supports and is supported by a satisfactory lifestyle.

Changed relationships

The onset of severe disability can have profound effects, not necessarily damaging, on existing personal relationships and on the formation of new relationships. Disability will change the roles people undertake in a relationship: for instance, a wife whose husband is disabled may find she has to manage the family's financial and business affairs for the first time, or a husband whose wife has been injured may have to undertake extra household tasks. The able-bodied person—husband, wife, or parent—may have to provide intimate personal care. The workload of everyone concerned is likely to be much greater. For many couples an active and satisfying sexual relationship will be possible, but it will be different. These changes, in addition to the feelings engendered by loss of function and its actual cause, are likely to have major repercussions.

Many spinal cord injuries happen to late adolescents or young adults at the stage when they are beginning to form relationships with the opposite sex and establish independence from parents, and when they may be very concerned at their ability to do so. It takes time and the realisation that people do think they are worthwhile before necessary self esteem can return. These adjustments are likely to take place after discharge from hospital, because then the issues become clearer.

Good community support, including practical help with the tasks of caring, and also the imaginative provision of resources to enable the person and carers to participate in normal community activities, are likely to help the process. Tired people who have limited social satisfactions will find it more difficult to make the necessary adjustments. Counselling can be a valuable source of help in making these adjustments. Studies indicate that people with spinal cord injuries are not as psychologically distressed or depressed by their injury as able-bodied people, including experienced staff, think them to be.

It is important to remember that many people with spinal cord injury do lead active, fulfilling lives, though it may take time to establish these.

Finance

Benefits commonly available to disabled people

Benefits to assist with disability

Mobility allowance (NI 211)

Attendance allowance (NI 205)

Industrial disablement benefit (FB 15; NI 6)

Rates relief for disabled people—information from district council

Income maintenance benefits

(1) Statutory sick pay (8 weeks) (NI 16) If in employment and not self employed.

Sickness benefit (28 weeks) (NI 16)	} Depending on sufficient National Insurance contributions
Invalidity benefit (NI 16a)	

(2) If not enough contributions:

Supplementary benefit (28 weeks) (SB 1) means tested

Severe disablement allowance (if eligible) (NI 252)

Supplementary benefit will "top up" any of the above if income below assessed needs level

(3) War disablement pension (MPL 153)

(4) Housing benefit (administered by district councils)

(5) Invalid care allowance (NI 212) (Paid to some carers)

(6) Family income supplement (FIS 1) If working, on low income and with dependent children.

DHSS leaflet numbers are given in parentheses.

Adequate finance is the major factor in determining successful rehabilitation, but many severely disabled people are living in poverty.

Not only do patients and their families have to cope with all the stresses of injury; they may also have to live on a severely reduced income which cannot support their existing lifestyle. In addition, it is more expensive to live as a disabled person. Mobility allowance and attendance allowance provide some help with the more obvious costs, but there is no provision for tasks such as household decorating, simple repairs, and gardening, which the disabled person may no longer be able to do.

Even if the person receives financial compensation, this will take several years to be granted and though interim payments can be made in some circumstances, they are not usually available at the time of discharge from hospital, when there is likely to be major expenditure on either moving or adapting the present house.

Because of the interruption in or possible loss of earning capacity many people will be dependent for long periods on welfare benefits administered by the Department of Health and Social Security. These are exceedingly complex, and various studies have shown that many disabled people are receiving less than their entitlement, sometimes by quite substantial amounts. Therefore, it is important for those working with disabled people to be aware that they may be underclaiming benefits and to advise them accordingly.

Adapting homes

	%
Able to return to own home with adaptations	59
Required rehousing, provided by district councils	21
Required rehousing, patient bought property	11
Required rehousing, provided by housing associations or through private renting	9

Figures derived from new injury discharges from Duke of Cornwall Spinal Treatment Centre in 1984-5.

Most houses are unsuitable for wheelchairs unless adapted. This presents a continuing problem, for while the patient may return to an adapted house or be rehoused from hospital, he may well want to change house in the future, especially since spinal cord injuries typically occur in young people, who would normally move house several times. A disabled person may have considerable difficulty in finding a suitable house, and there can be time restrictions on further provision of grants for adaptations. Many cannot afford to buy a house and will be dependent on council housing, housing association property, or privately rented property, all of which are in short supply. Consequently, any move of house can be difficult to achieve and has to be planned well ahead. The services of community occupational therapists, housing departments, and social workers may be required.

Employment

	%
Returned or planning to return to previous employment	33
Unable to return to previous employment and remaining unemployed	33
Unemployed before injury and after discharge	15
Started new employment	2
In full time education	17

Figures derived from new injury discharges from Duke of Cornwall Spinal Treatment Centre in 1984-5.

Employment is possible for severely disabled people, and for some the sense of achievement at being able to work is crucial to their self esteem. For others work is unimportant and coping with disability is challenging enough. A minority are able and keen to return to the work they were doing before the injury. It is important not to underestimate the adjustments of returning to live in the community and not to start work too quickly. The disablement advisory service and disablement resettlement officer of the Manpower Services Commission can provide advice and financial help to employers to make necessary adaptations to the place of work to enable the person to resume employment.

Information and advice on benefits

Department of Health and Social Security.
(Local office or Freephone DHSS)

Citizens Advice Bureau

Social services departments of local councils
Disablement Income Group (DIG),

Attlee House, 28 Commercial Street,
London E1 6LR (01 247 2128)

DIG (Scotland), ECAS House,
28-30 Howden Street,
Edinburgh EH8 9HW (031 667 0249)

DIAL [Name of town]. A voluntary
organisation operating in some areas.

Disability Rights Handbook.

Published annually by the Disability
Alliance, 25 Denmark Street,
London WC2H 8NJ (01 240 0806)

Spinal Injuries Association,
Yeoman House, 76 St James Lane,
London N10 3DF (01 444 2121)

Other local voluntary advice centres, many
listed in *Disability Rights Handbook*.

Many people will have to establish new careers, or will not yet have started work. It takes a considerable period of time, up to two or three years, to make sufficient physical and psychological adjustment to undertake an entirely new training or career. The careers service or Manpower Services Commission can provide careers guidance and help in finding employment, including the services mentioned above.

A considerable number of statutory services are concerned in providing services for disabled people. Voluntary organisations also provide important resources. They can act as pressure and self help groups, and organisations of disabled people have the knowledge and understanding born of personal experience. There are many such organisations, of which the Spinal Injuries Association is particularly relevant.

To mobilise and coordinate these services, which often vary in what they can provide in different geographical areas, is a major undertaking. Too often the disabled person fails to receive a service which would be of benefit or may feel overwhelmed and not in control of his own life with consequent damage to morale and health. The disabled person and family should have access to full information of the services available and be encouraged to make their own decisions about what they need within the constraints of what can be provided.

Mrs Erica Bamford, BA, is senior social worker, Mr David Grundy, FRCS, is consultant surgeon, and Mr John Russell, FRCS, director, Duke of Cornwall Spinal Treatment Centre, Odstock Hospital Salisbury.

Adapted from Office of Health Economics. *Mental Handicap: Ways Forward*. 1978.