ABC of Spinal Cord Injury

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TRANSFER OF CARE FROM HOSPITAL TO COMMUNITY

Expectation of independence

Paraplegic	— Independent
Low tetraplegic	— Independent or help required with bladder, bowels, and preparation of meals or largely dependent
High tetraplegic	— Totally dependent

Discharge from hospital is a complicated process for both paraplegic and tetraplegic patients. Physical care is a major concern, and here the difference between different levels of injury is profound. Paraplegics usually become self caring; those with low tetraplegia, especially if young, may also achieve independence, but those with high tetraplegia need someone else to take care of their physical needs to varying degrees.

Daily care

General care should include bathing or showering and inspection of the skin, particularly the pressure points, and toenails because ingrowing toenails are particularly common. Clothes should be made of natural fibre because many patients sweat excessively, and trousers must not be tight; otherwise there is a risk of pressure sores in the groin.

Bladder management—Tapping and expressing of the bladder at regular intervals, to achieve good bladder emptying, with drainage into a condom and leg bag collection system can be used by many men with reflex bladder emptying. The high tetraplegic can often tap for himself, but will be unable to fit his condom and leg bag or empty the bag. He also cannot make drinks for himself. Self intermittent catheterisation is the method of choice for most women paraplegics and some low tetraplegics, and also for an appreciable number of men. It is particularly successful in patients with an acontractile bladder. In women with high tetraplegia the bladder is normally best managed by an indwelling catheter. The alternative of having to be transferred on and off the toilet every three to four hours, and probably also being constantly wet, is not acceptable. Incontinence in women is probably the most difficult area of spinal cord injury to manage successfully.

Bowel management—Paraplegics and low tetraplegics are usually independent so long as they have access to a toilet with a padded seat to prevent pressure sores from prolonged sitting. High tetraplegics need a helper to do a manual evacuation on the bed every day or every other day.

Mobility—Paraplegics and low tetraplegics can usually transfer into and out of bed, a shower or bath, and a car, but the high tetraplegic has to be lifted or hoisted.

Male urine collection: different systems for day and night use. Day bag is smaller to fit under trousers; large night bag avoids need for frequent emptying and hangs on side of bed.

Who provides the care?

Family
District nurses
Care attendants
Community Service Volunteers
—independent living schemes
Resident carers
—privately employed
—employed by disabled person using state benefits

Care attendant schemes

National Health Service (NHS)
Social services
NHS social services joint funded
Leonard Cheshire Foundation
family support services
Crossroads care attendant schemes
Local charitable foundations

Respite care

Sessions every week
Fixed periods when disabled person goes to young disabled unit, Cheshire home, etc
Spinal Injuries Association care attendant to home for 1-2 weeks
Disabled person on holiday with volunteer group or care attendant

The care outlined implies a large time input and for the high tetraplegic this has to be done by other people. Who is to provide this care? The obvious answer is the family. However, it is unusual if the family can, or should be expected to, care for a highly dependent person alone for a lifetime. Traditionally, care for such people has been a choice between family or an institution, but over the past 10 years there has been a growing realisation that such highly disabled people want to maintain their independence and live in the place of their choice. This may be in an institution, but most wish to live in their own home. Outside help from the community will almost certainly be necessary to achieve this goal.

The resources available in the community for a particular patient are identified from the spinal centre by the social worker and community liaison nurse. The patient and his relatives must be kept fully informed so that correct decisions are made regarding his care in the community. Most patients with spinal cord injury are young men who were often in the process of making decisions about their lives before their injury. Immediately after such a catastrophic injury, and often for several years afterwards, they find it difficult to make major decisions such as where to live, with whom, and if necessary who is best to care for them, and what to do about their job. Sometimes a temporary solution is necessary, and allowance should be made for the possibility of later change.

A plan needs to be formulated, using the resources available in the area where the person lives. Services vary greatly between areas. The relatively new care attendant schemes are now available in many localities. They employ untrained people, under the supervision of a coordinator, to provide whatever physical care is needed. The emphasis is on encouraging the disabled person to control his own care—for example, negotiating when the care attendant comes to the house, so that he can plan with confidence his work, social life, and leisure time.

Community Service Volunteers now have an independent living scheme whose aim is to help disabled people live in the community. Volunteers live in the person's house or nearby and provide physical care and will often drive him to social occasions. Some determined disabled people have set up home on their own employing care attendants with finance provided from a combination of statutory funding sources. There are now several centres for independent living providing advice to help people to do this.

Immediately after discharge

When a patient with high tetraplegia goes home from hospital without any help from outside the family the pressure is often too great, and a breakdown of family relationships is likely. The patient and his family should accept maximum help initially, as the months after discharge are physically and emotionally exhausting for both. They are faced with the harsh reality of everyday living without the support and protection of a spinal injuries unit. Providing help to allow family members to have time for themselves is of primary importance; otherwise resentment at being tied for 24 hours a day will build up, along with physical and emotional exhaustion. Planned respite care is therefore a valuable provision, although initially the family may not be willing to accept this.

A case conference several weeks before discharge, with the patient, his family, hospital liaison nurse, general practitioner, community nurses, and care attendant coordinator, is a useful way of organising initial care for the high tetraplegic. It also means that all interested parties meet each other and exchange information on the patient's future care. A flexible approach is necessary as the problems vary greatly from patient to patient. In some cases the community physician or spinal unit staff will call a full case conference including representatives from social services and housing departments to discuss all aspects of the patient's future, including his care needs.

The initial plan might use a district nurse each morning with either a care attendant or family member to help her. The family would then be alone until evening, when a care attendant could come in to help undress the

Teaching session for families, in which all disciplines participate.

Education

Some pressure spreading mattresses

- Varying density foam laminated mattress (eg "Vaperm," single and double bed sizes, manufactured by Beauvale Medical).
- Static support system foam mattress (eg Polyfloat, single and double bed sizes, manufactured by Talley).
- Hollow core fibre padding (eg Spenco silicone padding from Spenco (UK) Ltd (Easicare polycare pad manufactured by Henlys Medical Supplies Ltd)
- Sheepskin—whole bed size

Talley skin pressure evaluator to measure pressure between skin and supporting surface.

Talley skin pressure evaluator about to be positioned under patient's ischial tuberosity; 60 mm Hg is safe for patients who can lift to relieve pressure and 35 mm Hg for those who cannot, choice of cushion being decided in part by these measurements.

patient and put him to bed. A care attendant or volunteer could come in for one or two sessions during a week to either take the patient out or enable members of the family to go out. This system can change as the family, disabled person, and care attendant become more confident, and the district nurses might then provide only the occasional check visit. More usually, they continue to do the manual evacuation of the bowels. The relationship between mother and son and, particularly, between young wife and husband is such that they may find it difficult to attend to bowels. Care attendants are usually not allowed to attend to manual evacuations.

Achieving good care depends on educating the patient, his family, and the community staff. The patient should be expert at understanding and, so far as possible, caring for his own body. He needs to be able to recognise potential problems and either deal with them himself or know where to go for advice.

The patient is taught how to use a mirror to check the pressure areas regularly. The wheelchair and cushion are best assessed in a pressure clinic. The patient needs a cushion which allows him to sit in the wheelchair all day without producing a red mark on the skin. Weight, muscle size, activity, ability to lift, nutrition, and posture all affect the type of cushion needed. Advice from the pressure clinic remains available to patients at every outpatient appointment, by telephone, and by referral from the community liaison nurse visiting at home. The choice of a suitable mattress is also very important. There are now many pressure spreading mattresses available, so that all patients should be able to sleep at least six hours without being turned.

By the time he is discharged from hospital the patient should feel thoroughly responsible for his own skin care. The appropriate family members are invited to the unit for individual instruction on how to care for their dependent relatives.

As spinal cord injury is uncommon district nurses and general practitioners may not have cared for such a patient before. District nurses, care attendants, and community service volunteers are invited to the spinal injuries unit to help care for their prospective patients. In our experience almost all those community staff invited welcome the opportunity to visit the unit. The community liaison nurse also visits community staff in their areas and will advise on request.

However well a patient's care is planned, there will often be gaps. For this reason, all patients are visited by the community liaison nurse within a month of discharge. The facility gives a continuity of care and on the spot advice for the many small problems that may arise.

Useful addresses—Association of Carers, Medway Homes, Balfour Road, Rochester, Kent ME4 6QU (0634 813981); Care Attendant Schemes, local social services departments have details.

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