

Continuing Care of the Spinal Cord Injured

D. J. Brown, M.B.B.S., F.R.A.C.P., F. K. Judd, M.B.B.S., D.P.M., M.R.A.N.Z.C.P., and G. H. Ungar, M.B.Ch.B., D.Phys.Med., F.A.C.R.M.
Spinal Injuries Unit, Austin Hospital, Heidelberg, Victoria, 3084, Australia

Summary

The functions of a comprehensive Spinal Cord Unit do not cease with the discharge of the patient from in-patient treatment after rehabilitation; they extend to after-care, both in medical follow-up and prevention and treatment of complications, and in ongoing support and education of the patient and his family.

An effective aftercare service must offer a life-long commitment to patients, and the aftercare team must include members of the disciplines which were involved in the initial rehabilitation, and also often others. Although demanding of time, resources and money, good aftercare is cost-effective in terms of savings in the cost of out-patient treatment and of re-admissions to hospital for the treatment of complications, and in maintaining many patients in the community, often as contributing members of society.

Introduction

Discharge from hospital after rehabilitation is a highly significant step in the care of the spinal cord injured. The philosophy of a comprehensive Spinal Cord Unit includes the re-establishment of family life, re-integration into the community and return to work and leisure activities as important aims of rehabilitation, requiring as much attention as the learning of new physical skills during active rehabilitation in hospital, or theoretical knowledge in the preceding sub-acute phase. All that has gone before has been to achieve this end, and the spinal cord injured person faces the prospect with joy mixed with fear, anxiety and misgivings. He may fear rejection, loss of respect, friends and job.

The involvement of the Unit with the patient continues after discharge from in-patient treatment, although the degree of this involvement, and the relative contribution of the various members of the team, will vary with the individual, his inner resources, external support and with the needs which will arise from time to time. Closer and more frequent contact will usually be needed in the first year, and especially the first few months following discharge, but lifelong aftercare will be needed in almost all cases.

Rehabilitation after discharge

The bridge between hospital and the outside world is a shaky structure, usually made of leave periods which are in many ways unrelated to real life. During these times the patient's status is special; nevertheless they show inadequacies and identify skills still to be learned. They enable discussion with staff and family members and foster growing confidence in personal, social and vocational skills. Outings to shops, a pub, a cinema, restaurants and sporting events prepare the patient to face the world from a wheelchair.

After discharge, the spinal cord injured person looks back from the other side of the bridge. He looks for ongoing support and reassurance, for a safe haven should things go wrong, for help with difficulties he and his family may face. He hopes it will become unnecessary to cross the bridge except for regular review.

Initial support will vary in intensity and must be tailored to suit each person and his particular circumstances. Team review should initially be made shortly after discharge, and then as often as is necessary for the first year or so. Such out-patient review will need to be linked with visits to home, community facilities and work place by different members of the team. The visiting nurse (Beer, 1984) plays a key role in this aspect of community re-integration but commonly social worker, sexual counsellor, physiotherapist, occupational therapist and recreational therapist need to do on-the-spot assessments in order to help the patient in the most effective way. Such visits emphasise the problems related to the disability and the handicaps imposed by the outside environment, and not to illness; they are therefore best dealt with in the environment in which they occur.

The vocational counsellor will be actively involved with many spinal cord injured patients at some time after discharge. After the initial re-establishment of family routines, most patients are able to face their employment options. Some may be able to return to the previous job, others to new roles with their previous employer. Some will consider new careers and require retraining. Computers have provided a large range of previously unavailable opportunities for the severely disabled in which they are able to compete on even terms. For those unable to work in paid employment, the vocational counsellor can play a key role in helping them to find fulfilment in voluntary community work.

Sport, recreation and leisure present their own challenges. Competitive sport may be an area where the spinal cord injured could be disadvantaged in competition with the able-bodied. Although direct competition is possible in some sports, e.g., archery, other sports have been designed or modified so that disabled participants can still have the benefit of physical competition (Nilsen *et al.*, 1985). Special efforts may be needed to help the more dependent spinal cord injured to take vacations or participate in leisure activities. Where possible however the post-discharge goal is integration with the general community.

Thus, the rehabilitation programme continues after discharge, based on the home and local community. With time, reliance on hospital personnel declines as family relationships stabilise, local support develops and re-integration into the community is completed. This time has its own particular problems—pre-existing individual, interpersonal and family problems may be exacerbated by

the injury; new problems may develop particularly in close interpersonal relationships, and sexual function may become more relevant and practical than it was in hospital (Ray *et al.*, 1984 I, II). This is part of the re-development of normal relationships, and advice may be needed from someone experienced in the problems of sexual dysfunction in spinal cord injuries. Fertility (Brindley, 1984) and special problems relating to sexual activity must be addressed when the spinal cord injured and partner are ready to deal with them.

Aftercare

Aftercare is a lifelong programme of preventive medicine, the treatment of complications, counselling and support both to patient and family as needed. It is uncommon to find as much effort, expertise, time and money devoted to aftercare as is given to the earlier aspects of treatment, and yet their ultimate aim is, or should be, to help the patient achieve as full, satisfying and healthy a life as possible, once in-patient rehabilitation is ended. When the work of the Spinal Unit is aimed at such an outcome, one may then reasonably redefine the aims of both acute care and rehabilitation as preparing the patient for successful aftercare.

Ideally, effective aftercare requires input from all disciplines involved in the earlier treatment of the patients—Occupational and Physiotherapy, Nursing, Social Work, Orthotics, Psychology, Vocational Counselling, Rehabilitation Engineering, and so on, as well as the Spinal specialist and other medical specialties, such as Psychiatry. In practice, this would make the aftercare team too large, and frequent, direct involvement of all disciplines with each patient is not necessary; if the members of the various groups are accustomed to working together, and have adequate experience of Spinal Injury work, a much smaller team can work effectively, and identify problems outside their immediate field for appropriate referral. For instance, any member of the team, but especially an experienced Social Worker, might suspect ‘masked depression’ or marital problems to which the patient does not admit.

It has been said that rehabilitation starts on admission to hospital. Similarly, aftercare starts with rehabilitation, as early knowledge of the patient’s personality and capacity, his family and support networks, his work and interests, facilitates goal setting, discharge and post-discharge planning with a better prospect of a successful outcome. This overlap between rehabilitation and aftercare indicates that it is advantageous for many of the same people to be involved in both areas; if aftercare is entirely the province of a group of staff discrete from the hospital rehabilitation team, the latter will not have as much knowledge and awareness of the expected life-style of the patients and the problems they have to face after leaving hospital. This knowledge obviously helps to make rehabilitation relevant to the ‘real world’ in which the patients will live. Conversely, awareness of the techniques and information the patients learn during rehabilitation makes it easier to find acceptable ways of meeting later difficulties.

As the patient settles into home routine and family life, the role of the rehabilitation team becomes less important. Health maintenance and prevention of complications become the main concerns of the team, as well as the timely

treatment of developing problems, so that serious complications may be avoided or minimised.

Traditionally, medical review usually at yearly intervals, aimed mainly at urinary assessment with urine culture, plasma creatinine estimation and intravenous pyelography, together with taking of a history and physical examination has been the norm. Recent assessment of IVP results has indicated a 3% detection rate of complications in previously anatomically normal renal tracts; the early complications so found may however be detected by less invasive means, such as plain x-ray and ultra-sonic scan (P. Rouse, personal communication).

Review provides the opportunity for exploration with the patient of new techniques, surgery and equipment. Tendon transfers now provide further independence for a number of patients. Penile implants (Iwatsubo *et al.*, 1986) provide new options for control of urinary incontinence and for sexual function, and sacral root stimulators for bladder control (Brindley *et al.*, 1982). Papaverine injections for erection (Wyndaele *et al.*, 1986) and electro-ejaculation (Brindley, 1984) for fertility are now routinely available. Functional electrical stimulation, though still experimental, is likely to provide increased opportunities for independence in the future. Evaluation of the usefulness of these advances to the individual enables a plan of management to be formulated and carried out.

Patients who live far from the Spinal Unit are often best reviewed by the team at a hospital or a similar facility nearer home. The local social worker is then an important recruit to the team, and local medical staff, physiotherapist and occupational therapist can be involved in the ongoing management of any problems detected by the team.

Particular attention is paid to those who are becoming increasingly frail and to those with a history of poor adjustment (Eisenberg *et al.*, 1985), for whom home visits by nurse and social worker are often an important part of long term follow-up. By the mobilising of support from local resources, these patients can often be kept functioning at home and out of hospital or nursing home for long periods.

Another aspect of aftercare by a comprehensive Spinal Injuries Unit is the re-admission, when possible, to the Unit of spinal injured patients suffering from illnesses, injuries or other problems, not necessarily related to the spinal injury. This reduces the problems arising due to secondary complications such as autonomic hyperreflexia or pressure sores, permits assessment of the effects of illness or injury on the patient's level of independence, and often greatly reduces the anxiety felt by patient and family in a strange hospital.

Effective aftercare is not cheap, but it is cost-effective, as it helps to keep patients living in the community instead of expensive nursing homes and hospitals, frequently in employment as productive and tax-paying citizens, and reduces the number of re-admissions to hospital for potentially preventable complications such as pressure sores (Bedbrook, 1985). A problem often encountered in trying to obtain adequate funding is that the savings made may be concealed in the total cost to the community, and may not be reflected in the individual balance sheets of Government Departments or Insurance Companies.

Is the investment of expertise, time and money justified on economic grounds, even if its humanitarian benefits are accepted? At the Austin Hospital, we have stabilised re-admissions to about 300 patients per year, without an increase in

the length of the waiting list. This is despite an increasing outpatient population, which is now approximately 1500 of the 2500 patients who have been through the Unit in the last 30 years. Even so, approximately 25% of these re-admissions are for the management of skin problems and urinary tract complications. Patients with pressure sores spend an average of 70 days in hospital. At \$390 per diem these preventable complications impose an enormous economic burden on the community. The prevention of one such pressure sore would save the salary of a visiting nurse or social worker. It can be readily seen that an active program of continuing care is both cost effective and good medicine.

References

- BEDBROOK GM 1985 Long term (extended) care—its importance and organisation. In: Lifetime care of the paraplegic patient. Churchill Livingstone, pp. 1–7
- BEER NIE 1984 The role of the home visiting nurse in the total education programme of spinal cord injured persons. *Paraplegia* 22(5):311–315
- BRINDLEY GS, POLKEY CE, RUSHTON DN 1982 Sacral root stimulator for bladder control in paraplegia. *Paraplegia* 20(6):365–381
- BRINDLEY GS 1984 The fertility of men with spinal injuries. *Paraplegia* 22(6):337–348
- EISENBERG MG, TIERNEY DO 1985 Changing demographic profile of the spinal cord injury population: Implications for health care support systems. *Paraplegia* 23(6):335–343
- IWATSUBO E, TANAKA M, TAKAHASHI K, *et al.* 1986 Non-inflatable penile prosthesis for the management of urinary incontinence and sexual disability of patients with spinal cord injury. *Paraplegia* 24(5):307–310
- NILSEN R, NYGAARD P, BJØRHOLT PG 1985 Complications that may occur in those with spinal cord injuries who participate in sport. *Paraplegia* 23(3):152–158
- RAY C, WEST J 1984 I. Social, sexual and personal implications of paraplegia. *Paraplegia* 22(2):75–86
- RAY C, WEST J 1984 II. Coping with spinal cord injury. *Paraplegia* 22(4): 249–259
- WYNDAELE JJ, DE MEYER JM, DE SY WA, *et al.* 1986 Intravenous injection of vasoactive drugs, an alternative for treating impotence in spinal cord injury patients. *Paraplegia* 24(5):271–275