

Care of a severely handicapped person over eight years: implications for the future pattern of community care

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SUMMARY. *This case report describes eight years practical experience of community support for a quadriplegic woman with progressive multiple sclerosis. Key factors in avoiding institutional care were the close collaboration between general practitioner, hospital consultant and social services, and the recognition by the doctors that the social dimension was the dominant requirement for support. Other important points were the identification of one key worker from the many professionals involved, and the use of separate NHS and social service funds to employ care attendants. This funding allowed community nurses to utilize their professional skills while the care attendants solved the problems of dependency. The mechanisms of community support for the individual are discussed in the light of proposed changes in the organization of care for the disabled.*

Introduction

WHILE current reviews^{1,2} emphasize the problems posed in providing community support for the elderly, mentally handicapped and mentally ill, the Griffiths report³ pointed out that 'younger severely handicapped people are also surviving longer with considerable care needs'. Recent reports have emphasized the lack of good provision made for younger physically handicapped people^{4,5} who are often neglected.⁶

This paper describes the community care of a young, severely physically handicapped person. Study of individual cases in this way helps to give a clinical foundation to policy documents and management strategies which are often based on theoretical grounds.

Medical and social history

The patient is now aged 47 years with progressive multiple sclerosis. She presented in 1968 with visual and urinary problems and the diagnosis was made in 1971; the disease has progressed through paraplegia to a total quadriplegia. There is no intellectual impairment.

The patient was divorced in 1976 and she lives with her daughter now aged 19 years. They live in a council house which has been heavily modified for the mother's use. She is entirely dependent on others for regular turning in bed, all movement, washing, dressing or feeding. Bladder and bowel function require specific care.

The main social problems are: housing, maintaining the family unit because of her young daughter, cooking, shopping, bill paying, holidays and mobility. The main medical problems are: pressure sores, bladder care, bowel management, personal

hygiene, eating and drinking, maintaining joint movement, maintaining physical health and mobility. There are also psychological problems: isolation and demands made on others.

Management

Crisis point

In 1980 the patient, then aged 38 years, developed a large ischial sore which did not heal despite surgical and medical intervention. At that time it was estimated that 80 hours per week were committed to her support mostly by the community nursing service but also by social services.⁷ This included increasing periods of time related to the frequent demands for services which the professionals felt were inappropriate, for example feeding the cat. In addition two calls were made to the patient every night by the nursing service.

In 1981 a crisis was looming, because of the considerable stress among the professions involved with caring for the woman. Inter-professional problems were experienced on a daily basis. It was realized that if a strategy of care at home could not be devised the patient would require prolonged hospital care with foster care for the daughter, then aged nine years old.

Many case conferences were held with senior representatives from all the professions involved. An analysis of the patient's needs during a 24 hour period enabled the problems to be defined (Table 1) and possible solutions to be outlined. This showed that she could be safely left at home for periods of three hours per day without assistance. Transfers, mobility and food preparation and feeding could all be met by suitably trained members of the social services team — care attendants. The family unit (mother and daughter) could thus be maintained within the community.

Care plan

A plan involving close liaison of home care workers, care attendants and community nursing services was devised (Table 1).⁸ This plan allowed the patient to be moved at regular intervals and ensured that she was not left alone for longer than three hours,⁹ thus avoiding the isolation which had contributed to frequent calls previously being made on carers (usually nurses).

It was found helpful to have the advice of a person removed from the everyday care of the patient — in this case a consultant in rehabilitation. The outside expert helped the patient to understand that frequent demands on the caring agencies could result in her requiring admission to a unit for young disabled people, with the consequent break up of the family. This was helpful in negotiating and implementing the care plan.

Conferences between doctors and social service managers helped coordination on the political front and practical coordination was aided by regular meetings between the social services key worker and district nurse. The key worker was the professional worker identified to be responsible for the coordination of team activities and for communication between all professionals involved in health and social services. This avoided differing messages being given by various workers, and helped maintain cooperation between team members. The case conferences facilitated communication and provided encouragement

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Table 1. Solutions to the medical and social problems of one disabled woman.

Problem	Solutions
<i>Medical</i>	
Pressure sore	Low air loss bed, Roho wheelchair cushion. Daily dressing by district nurse
Bladder care	Indwelling urinary catheter; bag emptied by care attendant
Bowel management	District nurse manages twice weekly
Turning at night	District nurse calls twice each night
Maintaining joint movement	Domiciliary physiotherapist visits twice weekly
Personal hygiene Eating and drinking	Practical help provided 3 hourly by carefully coordinated programme of timed visits by district nurse, home care worker and care attendant
<i>Social</i>	
Housing	Council bought house and social services installed wheelchair lift and carried out numerous minor adaptations and major structural alterations.
Young daughter	Largely independent. Care attendant helps with getting off to school. Close mother/daughter relationship maintained.
Cooking, shopping, paying bills	Home care team (care attendant and home care worker) manage
Holidays	Annual holiday and regular meetings with the MS society
Mobility	Care attendant transfers from bed to chair using electric hoist. Electric client-operated wheelchair. Stepmaster provided to cope with front door steps

to the various helpers who were becoming unable to cope with the increasing problems of this patient.

Outcome

Since 1982 the ischial sore has broken down on only two occasions, necessitating bed rest for the patient at home on her low air loss bed. Figure 1 shows that the number of days that the woman spent as an inpatient have decreased after the introduction of the new strategy.

There have been problems, however. Working in a large team has meant that it is not always possible to maintain the morale of field workers. Indeed in April 1986 hospital admission was arranged because of stress within the team of community workers. It was felt that a short planned hospital admission would avoid long term problems.

Following the successful implementation of the care plan three has been discussion about terminal care, place of death and about who would care for the daughter during and after the mother's death.

Discussion

The problems encountered with providing care in the community for this individual were multiple; there were no easy solutions and no satisfactory endpoint. Care at home would be ongoing, would involve many workers and might mean increasing commitments. Admission to hospital or a unit for the young disabled would be against the patient's wishes and would cause pro-

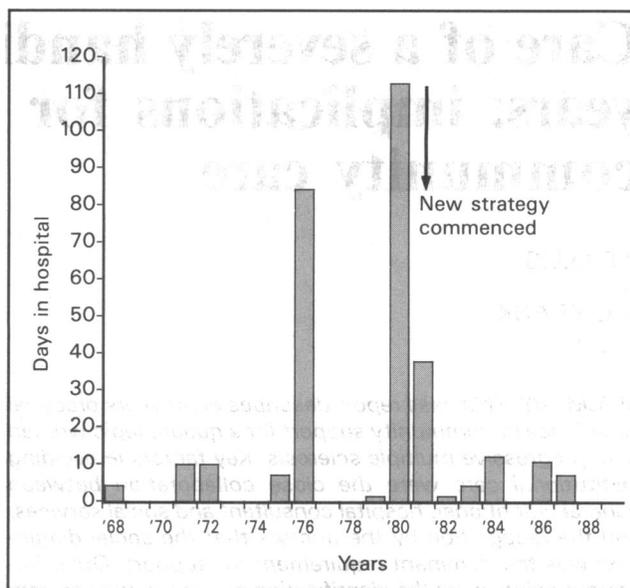


Figure 1. Hospital utilization of a patient with progressive multiple sclerosis before and after the introduction of the 'care attendant scheme'.

blems for the family unit. The skill and time of many different professionals were needed from both the health services (community nurses, general practitioner, and hospital) and social services (care attendants, disabled living advisers [occupational therapists] and social workers). Such plans are needed for many severely handicapped people.¹⁰

These plans were complex because of the patient's multiple disabilities and the number of people involved in her care. This case study illustrates that a carefully formulated strategy is essential in the care of any person for whom good teamwork is necessary for continued community care.

Key factors in the development of good interprofessional relationships were an appreciation by health professionals of the dominant nature of the social dimension of her care and the willingness of medical staff to work with the social services management.¹¹ This guaranteed support for the community workers when required by both the general practitioner and the hospital. It also facilitated the generation of financial support from the health service which was required to support the financial contribution from social services (each agency provided half the funding for the care attendants). In this instance, joint funds³ were not used although subsequently extensive use has been made of this form of financing for various care attendant schemes.¹²

As part of a multidisciplinary team, the general practitioner needs to be positively involved in the identification and care of disabled patients.¹³ The Griffiths report identified general practitioners as playing a crucial role in this area, a role which may not always be recognized.¹⁴ General practitioners have existing relationships with the primary care team, social services and with the patient. However, severe disability has profound effects on existing personal relationships and the formation of new ones. These problems may affect relationships between client and professionals and between professionals, and can adversely affect good team functioning.

This case demonstrates that given adequate resources, the primary health care team can manage severe bed sores in a severely disabled person at home. Many disabled people have to accept residential care because they are unable to gather the intensive support they require to remain at home.¹⁵ The relevant

medical and social services often lack coordination and have little clear sense of direction.^{1,16} The case conferences enabled the four criteria of good community care to be met by defining objectives, involving all agencies, using the best professional advice and utilizing all community resources.²

The fact that this individual's community care required capital expenditure on a special bed illustrates the importance of a capital budget in support of the primary care team. It has been estimated that the total cost of the combined 'package' of health and social services in cases such as this are considerably more than the cost of residential care.¹⁷ This was not predicted by the Griffiths report. However, there are likely to be substantial reductions in admissions to the acute sector and this poses the problem that the savings accruing to one budget may be at the expense of another.¹² The government proposals on the future of community care simplify some of the administrative problems but resources will still be fragmented. However, local authorities may be more willing to provide care attendants in future rather than carry the cost of residential home care for severely handicapped people.

As a result of the successful support strategy for this patient the 'care attendant model' has been used to assist other younger disabled people in Harrow to maintain their independence within the community, thus illustrating how the care of one individual by interested clinical staff can contribute to the development of general management strategies.

References

1. Murphy E. Community care I. Problems. *Br Med J* 1987; **295**: 1505-1508.
2. Murphy E. Community care: possible solutions. *Br Med J* 1988; **296**: 6-8.
3. Griffiths R. *Community care: agenda for action. A report to the Secretary of State for Social Services*. London: HMSO, 1988.
4. Royal College of Physicians. Physical disability in 1986 and beyond. *J R Coll Physicians Lond* 1986; **20**: 160-194.
5. Beardshaw V. *Last on the list. Community services for people with physical disabilities*. London: Kings Fund Institute, 1988.
6. Bax MCO, Smyth DPL, Thomas AP. Health care of physically handicapped young adults. *Br Med J* 1988; **296**: 1153-1155.
7. Burnfield S, Frank AO. Multiple sclerosis. In: Frank AO, Maguire GP (eds). *Disabling diseases: physical, environmental and psychosocial management*. Oxford: Heinemann, 1989.
8. Ellis PF, Frank AO. Care of physically handicapped young adults. *Br Med J* 1988; **296**: 1673.
9. Price T. Aspects of social work involvement in rehabilitation. *Demonstration Centres in Rehabilitation Newsletter* 1982; **28**: 91-98.
10. Bamford E, Grundy D, Russell J. Social needs of the patient and his family. *Br Med J* 1986; **292**: 546-548.
11. Corney RH. Social work and primary care — the need for increased collaboration — a discussion paper. *J R Soc Med* 1988; **81**: 29-30.
12. Townsend J, Piper M, Frank AO, et al. Reduction in hospital readmission stay of elderly patients by a community based hospital discharge scheme: a randomised controlled trial. *Br Med J* 1988; **297**: 544-547.
13. Williams EI. The general practitioner and the disabled. *J R Coll Gen Pract* 1983; **33**: 296-299.
14. Hull R, Frank AO. General practitioners' responsibilities. *Br Med J* 1988; **297**: 792.
15. Gloag D. The dynamic approach to residential care of the disabled. *Br Med J* 1984; **288**: 1323-1324.
16. Tulloch AJ. Prevalence of disability observed in an Oxfordshire practice. *J R Coll Gen Pract* 1985; **35**: 368-370.
17. Prouse PJ, Brill M, Townsend J, et al. Costs of community care for younger disabled people. *Int J Rehab Res* 1987; **10**: 352.

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