LIFE AFTER HEAD INJURY

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This article examines the longterm sequelae of head injuries and describes the development of the post of Acquired Brain Damage (ABD) Coordinator as part of the local response to this needy group.

INTRODUCTION

Lancaster, in common with many other areas, has no specialised intensive care rehabilitation or longterm care facilities for adults with acquired brain damage. As a consequence, their rehabilitation often takes place in a wide variety of local settings, in a limited way, supported by good-willed staff with limited resources, not ideally equipped to deal with the particular and demanding difficulties which these patients and their families can present.

The aim of this article is to describe how the interventions offered by the Lancaster-based ABD Coordinator have begun the process of improving the situation for this complex group and their carers.

HEAD INJURY: ITS SCALE AND NATURE

A considerable amount of research exists regarding the epidemiology of traumatic head injury. It establishes that head injuries are common, with incidence rates of eight severe, 18 moderate and 250-300 minor head injuries per 10,000 population per annum(1). Given that the population within the Lancaster district is approaching 133,000, the likely annual incidence of head injury is:

● Severe head injury	11
● Moderate head injury	24
● Minor head injury	320-400

The incidence of survivors with longstanding severe disability is 100-150 per 100,000(2), therefore the Lancaster district will have 130-200 living in the area at any one time, and after initial survival, life expectancy is almost normal.

Head injuries most commonly occur in young men between 17 and 22 years old. Road traffic accidents are the most common source of injury (40%)(1). Other causes are assaults, falls, sporting accidents, toxins, poisons, infections and failed suicide attempts. Studies also show that up to 60% of all head injuries are alcohol-related(3). The longterm sequelae of a brain injury can be profound. The nature and presentation of difficulties can range from mild cognitive problems to severe physical disability, sensory losses and gross behavioural problems. Many brain-injured people have multiple problems which, whilst challenging health and local authority services, more importantly significantly affect their ability to function within the family, work and community settings(2). This is because, whilst studies indicate that 90% of adults with moderate or severe brain injuries make a good physical recovery, the enduring areas of difficulty involve cognitive functioning and behavioural control(2). In 1967, London(3) described a syndrome called "Lame Brain": components of the syndrome include childlike selfishness, severe personality change, irritability and aggressive behaviour. These catastrophic changes place huge, often impossible, demands upon a family. High levels of stress often become distress as time wears on. In 1995 the Joseph Rowntree Foundation published the results of an intensive anthropological study of 20 families in which there was a young person who had recently suffered a severe head injury(4). The results damned the responses from the services. Families felt dissatisfied with the level of care provided on general wards, critical of the premature withdrawal of support services when the psychological and social repercussions of the injury continue indefinitely, and carers requested more specific advice, support and specialist counselling in a wide range of issues, including the medical position, emotional problems, relationships and employment issues.

DEVELOPMENT OF THE COORDINATOR POST

Against this huge backdrop of unmet needs, with a group which does not easily fit into broad categories such as physical or learning disability, the post of ABD Coordinator was established. In 1993 the 'ABD working group', made up of representatives from health, social services and the local Headway (the National Association for Head Injuries) group, successfully bid for two years' funding for a coordinator. The funding came from a pocket of 'joint finances' monies, put up by the health and local authorities to get new projects off the ground. In 1994 the coordinator was in post part-time and in 1996 the funding was extended to fulltime for a third and final year.

ROLE OF THE COORDINATOR

The overall aim of the ABD Coordinator's service is to coordinate the provision of a comprehensive range of services to meet the specific needs of adults with acquired brain damage and their carers, in partnership with statutory, voluntary and private agencies. The prime groups for targeting are:

- those people who have difficulties as a result of a traumatic brain injury, their families and carers
- 16-65 year olds
- usually resident in the Lancaster district
- those injured in adult life

In order to achieve the aims of the service the coordinator's time is split between service development and a clinical input as 'head injury case manager' for individual patients. Service development involves liaising with multi-agencies in a wide variety of settings, organising training sessions and monitoring and making recommendations for service improvements for adults with brain damage. Working as a head injury case manager includes representing, advocating for, and coordinating interventions across health, social care, education, work, housing, legal and leisure domains: ensuring that the brain-injured person gets the right help at the right time (see Figure 1).

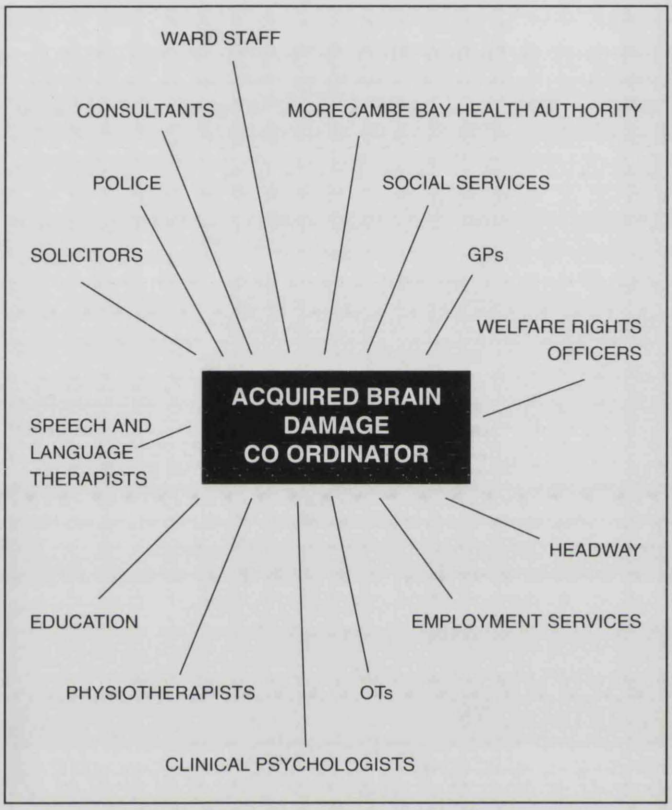

Fig. 1 – Working Relationships

WHAT DOES THE COORDINATOR ACTUALLY DO FOR PATIENTS?

The Coordinator has an office at Lancaster Moor Hospital, from which the following services are provided:

- assessment of newly head-injured clients, normally within seven working days
- recommendations for the rehabilitation needs to medical staff, and advocating for these with the health authority purchasers
- directly advising ward and therapy staff on management and interventions
- providing information and counselling to relatives
- running a bi-monthly special interest group for staff involved in the care and treatment of people with head injuries
- liaison with voluntary and statutory bodies and carers to facilitate the brain-injured person in his reintegration into the community
- running a weekly head injury clinic at St Martin's College, offering assessment and treatment on cognitive and perceptual problems
- liaison with the local Headway group, attending both weekly and monthly Headway group sessions and encouraging their development
- out-reach service in the community, taking the service into the person's home, work and leisure environments

REFERRAL TRENDS

During the period between February 1994 and December 1995, a total of 90 patients were referred to the Coordinator. An average of 2.3 new patients are referred to the service each month. The main sources of referral are as follows:

● hospital nursing staff at Royal Lancaster Infirmary	29%
● therapy staff (physio, OT)	17%
● consultants	12%
● Headway local self-help group	11%
● GPs	10%
● individual/carer	4.5%

Other sources of referral include clinical psychologists, social workers, community psychiatric nurses, day care, district nurses and disability employment advisers.

PROFILE OF PATIENTS

Of the 90 patients referred, 70% were men and 30% women. The majority of patients are young, with 46% in the 16-34 year old range, and 35% aged between 35 and 54 years old. The majority of patients had a recent head injury, with 51% having a recorded date of injury between 1990 and 1995. The next largest group (17%) had a recorded date of injury between 1980 and 1985 and a few (9%) were recorded pre-1965.

SERVICE OUTCOME

As the clinical role of Coordinator is that of a case manager, outcomes are best illustrated in terms of end results. In reviewing 53 patients being managed, statistics reveal that each person received a number of interventions, linking them into appropriate resources. These are indicated below:

Interventions in hospital

contact initiated with GP	28 patients (53%)
advice given to hospital staff on the management and placement of patients	25 patients (47%)
counselling of carers	22 patients (41.5%)
referrals to social services and/or welfare rights	22 patients (41.5%)
advice and information given to carers on available resources/services (eg Headway, Citizens' Advice Bureau)	18 patients (34%)
information given on specialist solicitors	17 patients (32%)
placement organised with specialist rehabilitation centre	6 patients (11%)
contact with police	6 patients (11%)

Interventions in the community

liaison with GPs	42 patients (79%)
referral made to consultant therapists	43 patients (79%)
liaison with social services for ongoing community care	39 patients (73.5%)
information given on voluntary organisations	32 patients (60%)
counselling and support given to patients and carers	31 patients (58%)
placement in sheltered work setting organised	28 patients (51%)
patients introduced to adult/further education	11 patients (21 %)
information given on specialist solicitors	10 patients (19%)
referral made to disability employment adviser	10 patients (19%)
maintaining patient in open employment	9 patients (17%)
liaison with police/probation service/CPS	7 patients (13%)
patients introduced to leisure services (eg Salt Ayre)	7 patients (13%)
liaison with housing department	5 patients (9.5%)
referral to head injury clinic	4 patients (7.5%)
referral to specialist rehabilitation centre	3 patients (5.5%)
referral for residential care	2 patients (4%)

The figures reflect the coordinator's varied role in working with people with multiple and complex problems across agency boundaries.

FACING THE CHALLENGES

When considering the challenges and potential obstacles to the success of the ABD project, then myths and financial restrictions rank high.

Myths

Many myths and inaccuracies exist regarding the exact nature and consequences of head injuries. Relatives often say that they have been misinformed about diagnosis and possible outcomes – "We were told to put our son in a home . . . he was a cabbage case . . . the man said he would never be able to do anything for himself." I welcome opportunities to provide information, advice and training for anyone involved in caring for people with head injuries. I coordinate a bi-monthly special interest group and in February 1996 organised a Head Injury Awareness day which attracted over 70 delegates. Another training day is planned for September, this time targeting medical staff and GPs. I am a member of the local Headway group, which is currently campaigning for a Headway House, which will be a day centre for the Morecambe Bay area offering ongoing therapy and social support for those coping with brain damage.

Funding

The clinical role of head injury case manager has been identified as an important role to help patients access many services(5,6). The existing service for the Lancaster district is provided by one person with a heavy longterm caseload, which increases by an average of two new clients each month. Funding for the post ends in January 1997. Unless additional sources of funding can be identified, the service will end, with the ultimate withdrawal of support to the present active caseload of 32 clients. In the current financial climate, it is recognised that there is little likelihood of any one organisation being able to provide full funding for the post. It is more likely that there may be a development of small contracts – for example, sponsorship by Headway-affiliated solicitors, statutory agencies and GP fundholders.

CONCLUSION

The Lancaster district's ABD project has run now for just over two years, accepting referrals for both old and new head injuries. In developmental terms it is in its infancy, and crude outcome measures indicate positive benefits within a relatively short time at low costs.

Finally, the project can never be a substitute for the development of services which address the needs of people with head injuries. What it does, however, is to offer a focused foundation for doing so in the future.

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