Consumers' View

The game of head injury hop-scotch, UK style

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When the Princess of Wales made her plea for personal privacy it was, according to the press, "at a charity lunch." The charity concerned was Headway, which exists to help and support those who have suffered a head injury and their families. On that particular day (3 December 1993) the princess herself received massive publicity, but sadly Headway did not. Apparently the predicament of one lonely woman was more manageable in media terms than the acute suffering of the people she was supposedly there to draw attention to. So to the public the plight of living life after a head injury remains meaningless – a state of affairs which should be rectified by informed medical and social debate and yet this is not being achieved. The treatment of head injury, and more specifically the rehabilitation and after-care maintenance needed to support those with head injury, remains in the medical backwoods. Yet every year the number of severely brain damaged people surviving accidents increases because of the transcendence of technological prowess over brain death. Headway estimates (no accurate figures are recorded anywhere about head injury nationwide) that the number of people with severe brain damage is currently 120 000 and that the figure is growing by about 11 000 each year. To health service managers these may not seem significant numbers, but they should beware of putting people with brain damage on the back burner in terms of healthcare planning because such people will never get better and go away. On the contrary, they will usually become more difficult and dependent and will then almost certainly cause a disproportionate amount of workload and finance to place and maintain, whether in the community or in institutional care.

Unpalatable consequences of head injury

The trouble with head injury is that it isn't cuddly. No expert surgery or inspired therapy

can make people with head injury as they were before (and of course they may not have been at all cuddly initially). So they become unpalatable, usually first to their old friends and, often, in future years to the members of the family who struggle valiantly to look after them and, in more severe cases, contain them. People with head injury often find concentrating difficult, therefore their ability to work efficiently is diminished. Often they have personality overload and are too exuberant or friendly (imagine how you would cope with a large 25 year old man who wants to talk and play with every small child he encounters in a shop or park). In other cases they are left with nothing to say for themselves and merely sit around in a wholly passive state. Many of those with severe head injury will not necessarily be fully aware of what they are compared with what they were, but we can be sure that most people with moderate head injury do comprehend this awful discrepancy and that this very realisation works as a contributory destroyer of a self esteem already at rock bottom.

For health workers and social workers too head injury doesn't seem to appeal as an attractive career option. When it does, and thank God it does to some dedicated professionals, the individual care is usually excellent, and in that locality the families affected by head injury can count their blessings. But the random nature of such professional interest and expertise inevitably leads to an inequality of head injury services between different regions. Without the determination of medical professionals to promote services for these people, certain regions will, it seems, remain largely bereft of services for this client group. Is the Department of Health aware of this? What are the implications of this kind of inequality for those with head injury in regions without head injury programmes? Do those people not have the same rights as any other sick person, or are health service managers allowing them to be assessed by experts from other medical disciplines who are not really capable of recognising the clues of cognitive or behavioural dysfunction and thereby depriving this group of people of their just deserts?

Social services need to realise that most people with head injury are young (in the age range 18–30) and so may well have a lifetime need for care and advice. What kind of care plans have they devised for those so called moderately injured people now in their 40s who are being cared for by aging parents, once

those parents can no longer manage? Does each person have a named social worker known to him or her and the family (and of course the general practitioner) who is responsible for ensuring that the family is making plans for the future when the main carer may no longer be able to initiate care? A second salutary fact is that head injury often leads to behavioural problems, which will mean that those people cannot simply be found housing and then left in the "community" to get on with life – or at least not without dangerous repercussions. Unfortunately for all of us the condition of brain damage cannot be cured by drugs or surgery, it can only be handled effectively and efficiently by structured ongoing and consistent support. This support cannot be supplied by inexperienced social workers who know nothing about disability. Have any social services departments actually set up training programmes for their social workers so that they can become effective practical advocates for people with head injury in the community?

Hotch-potch of aftercare service

The national office of Headway at Nottingham is merely the nerve centre of a network of local Headway groups which are funded by local fundraising efforts, staffed mainly by volunteers, and organised according to local need. Many groups have set up Headway houses, which are in most cases quite simple day clubs where people with head injury can spend time (once or twice a week) once they have left hospital. The houses serve as places of last resort for many of them who have literally nothing to do and no one to see from one week to another. Some groups who have particular drive and ambition, usually helped by individual professional commitment from a local psychologist or other medical professional, have begun to attempt a more professional service. Generally speaking, in areas where there are no specialist rehabilitation centres, local groups are beginning to look into the possibilities of joint funding from either local health authorities or social services to provide therapeutic services such as physiotherapy for their members. Laudable as this sounds in theory, it has to be said that such schemes are being set up on a completely ad hoc basis with no national coordination and no official recognition by the Department of Health. Should Headway be attempting to fill the gap in services left by government policy without questioning whether, as a charity, it is truly able to offer anything more than a surrogate service? The dilemma for Headway of "surely anything is better than nothing" is certainly a fundamental one. But it is even more serious for consumers, who should be asking whether this is the best that their region can do. On what basis has the region settled for a surrogate rehabilitation programme run by a voluntary agency which is subject to the annual whims of district purchase plans? Where is the organised, rational continuity of seamless care here? If ever there was a patchwork (or perhaps, more accurately, hotch-potch) of services, it is here. Is there any official policy which sanctions

such an anarchic cocktail of care for severely disabled people? As a consumer I would like to know.

My basic agenda (which is purely personal and not necessarily supported by Headway) is as follows:

- Head injury cannot be neatly categorised as just a physical disability, a learning difficulty, or a psychiatric disorder. The reality is that it can be a little (or a lot) of any one, or even all three, of these
- Head injury is not just a medical problem that can be sorted out in hospital. It is a condition for life which needs the kind of medical and social support which is expert and flexible
- People with head injury need active support and encouragement to lead the rest of their lives to the best of their diminished abilities. This means the active cooperation of social services
- People with head injury need active things to do in the home or in the community, on a regular basis
- Families coping with a relative with head injury need a great deal of consistent regular medical advice and informed social support. Surely most health service professionals would applaud these basic tenets. Yet in how many regions are they actually achieved? In how many regions can health service managers honestly say that they have taken most of these points on board and are really looking at ways of making these things happen? In how many cases of head injury is mere lip service paid to the idea of case managers who follow a patient through hospital and out into the community? Do hospital authorities really coordinate with local social services to ensure that people are getting the follow up care and support they so desperately need? How many social workers or case managers are there who are actively involved in their local Headway groups or have been properly trained to cope with head injury? As a consumer, I don't know the answers to these questions, but I would very much like to know.

Specialist help

There are 12 specialist centres for brain injury rehabilitation in the United Kingdom. Under the 1991 healthcare reforms many of these centres have, out of necessity, pitted themselves against larger outfits, specifically community units, in an effort to persuade purchasers to buy their services. Because getting people back home as quickly as possible and thus back "into the community" has become a blanket touchstone of government policy community based care has seemed both a cheaper and more politically correct option for purchasers. In the case of severe head injury this is quite clearly out of the question – painstaking specialist care over many months is a prerequisite. Yet I would argue that for almost any person with brain injury generalist therapy on an ad hoc basis is nowhere near good enough and will inevitably lead to crisis management. Specialist expertise held at a central core on a regional basis is essential for

the ongoing care and understanding for *all* such people and their families. Rather than hoping that community nurses or physiotherapists can monitor people with head injury in their locality, why not instead actively encourage specialist units to evolve a really effective outreach service, with training facilities for therapists and nurses who can then be deployed from the centre at local level? Consumers of head injury services value specialist help and advice enormously. It is probably the most vital component in the battle for creating a kind of quality of life. Much as health service politicians might like the idea of getting people home as soon as possible, people with experience of the effects of head injury know that this is not the answer. The family need time to readjust their own outlook, so specialist help, compassionate nursing homes for those with head injury, and respite care are essential if families are to stay the course of lifetime care. Purchasers need to understand that family and marital care are not immutable. They, just as much as hospital services, have a real cost to society. People are not born to be round the clock carers for life, and they can reject that responsibility at any time. This needs to be addressed politically and should be included in any long term health planning for head injury services. Generalist help is what many people with head injury have been receiving for the past 30 years, and it is not good enough in terms of quality, continuity, or reliability. It might stave off imminent family disaster but not for long.

Under the terms of the Community Care Act every person leaving hospital with a disability is entitled to a formal assessment of his or her condition and needs, yet in areas without this expertise to hand, how can such assessment be conducted? Even where such assessments are carried out and a continuing care plan is drawn up, what checks are there by purchasers that these plans are even implemented? When considering quality of care healthcare professionals should ask themselves what they mean exactly. It is a well acknowledged fact that head injury victims generally receive good care in acute wards of the general hospital but that the so called Cinderella service of rehabilitation and thereafter is where things begin to go wrong. It seems to many consumers with experience of the effect of head injury that this pattern has changed very little since 1991. Little in the way of improvement in liaison between the general hospital, the rehabilitation centre, or the social services has actually changed *in practice*. Perhaps the Department of Health needs to draw up a model of interaction which clearly delineates the different and yet complementary roles of healthcare workers and social workers. Then, having set up the channels of co-operation, regions need to recognise that it is not enough to say that case managers should exist to promote the wellbeing of disabled people. After all, what is the point of producing a document which recommends day care centres, or retraining opportunities if these facilities do not even exist to be purchased in

the region concerned? Perhaps the emphasis placed on expert assessment and the production of well documented care plans is yet another palliative. The whole notion of expert assessment is after all quite irrelevant in consumer terms if nothing can be actively improved by such work. Would anyone be interested in buying services from an amalgam of such bodies as social services, rehabilitation centres, and charities such as Headway or the Shaw Trust (an employment agency for disabled people) if they could put their heads together and establish some kind of workable aftercare programme in which an individual curriculum could be devised for each patient?

My last question for any health service professional reading this is how to define rehabilitation. What do you understand by this word and how do you imagine the rehabilitation needs of your own region? Recently the Department of Health pledged to establish 46 new consultancy posts in "rehabilitation," but has anyone been told what this new medical discipline consists of with regard to clinical training and expertise? Surely not every person in a wheelchair has the same medical needs – some may be arthritic, some may have head injury, and others may have motor neurone disease. Can any one consultant truly be expert enough to care for diseases as disparate as these? Certainly the notion of thrusting rehabilitation higher up the medical agenda is a good one, and certainly the promise of experts who can give practical help and advice to people with head injury on their future lives is vital, yet there must still be misgivings about the necessarily "generalist" nature of this new specialty. For example, can those with experience in caring for head injury be certain that the new rehabilitationists will have had the requisite clinical neuro-rehabilitation experience to treat us properly? Can we be certain that the complexities of neurological as opposed to physical disability will be dealt with expertly, or are we once again being forced into a system which has not been constructed with us in mind but rather for those with physical disabilities? Cynical questions, maybe, in the light of an apparently forward thinking policy, but we have to fight our corner to prevent the tragedy of being overlooked once again in the managerial struggle for economy and uniformity.

I would like the Department of Health to set up a forum on head injury, initially to find out how many people with head injury exist in the United Kingdom and in what kind of state they survive. Then I would like one person in each region to find out and monitor what happens in their region and to compare it with a national model. Only in this way can the present threadbare patchwork of care for people with head injury be turned into a fabric strong enough to enfold all those who desperately need security and continuity. I cannot quite bring myself to suggest a charter for people with head injury, but perhaps someone else will do it for me?

What a pity that Mark Hebdon in *The Archers* did not survive his car accident. In the story he died after his car (and presumably his head) hit a tree. In the real world, of course, Mark would have been rushed to Dorsetshire General Hospital and survived massive brain damage only to live a life so severely curtailed that no longer would he need his new cricket bat (a birthday present from his wife), never again would he be able to enjoy candlelit

dinner with Shula, his wife, and certainly his legal partnership would have folded.* But of course that, like the mention of brain damage at a charity lunch, would affect the listening figures.

* Mark Hebdon was a young central character in *The Archers*, the longest running radio soap series broadcast by the BBC. His death in the series was reported in the national newspapers.