

The social repercussions of severe head injury

When a young adult suffers a severe head injury it is frequently the families who become the main supportive unit. Parents demonstrate considerable commitment to their adult children, but an intensive study of twenty families has shown that responses from support services are often inadequate and short-lived and do not sufficiently recognise the long-term effects on family life and relationships. Jane Hubert of Southampton University found:

f Parents praised the initial life-saving care given in hospitals but many were dissatisfied with the subsequent level of care provided in general wards.

f Although the psychological and social effects of severe head injury may continue indefinitely, supporting services tend to be withdrawn at an early stage.

f Families felt they would have benefited from more advice, support or specialist counselling on a range of issues:

- **The medical position:** Both in the very early stages and later, families felt they needed more and clearer medical information on the effects of the head injury and how the injured person's condition might change over time.
- **Emotional problems:** The feelings the young people may have, such as anger and frustration, difficulties with relationships, and the uncertainties resulting from the changes in themselves, as well as the effects these have on other members of the family, often appear to be ignored after discharge from hospital.
- **Family relationships:** The return to dependence just when young adults were beginning more independent lives can cause tensions for both parents and young people. Sisters and brothers may also feel pushed to one side and at the same time have to establish a new and often problematic relationship with their sibling.
- **Social lives.** Old friends tend to drop away, leaving the young person even more isolated and dependent on the family.
- **Work.** Attempts to return to training or work tend to be unsuccessful because employers and colleagues - however well-intentioned - have inadequate knowledge of the effects of severe head injury.

The hospital experience

When someone is taken to hospital with a severe head injury, in a coma, it is their families who experience the immediate shock and uncertainty of the situation. Almost always they are told that their son or daughter may well die or, if not, will survive only in a persistent vegetative state. At this stage, there seems to be little attention paid to the plight of the families, who would have benefited from support and counselling from the very beginning.

All the parents praised the high standard of medical care in Accident and Emergency and Intensive Care Units, although many would have liked to be given more information, and sometimes felt that doctors assumed they were incapable of understanding.

However, in many cases the move from intensive care into a more general ward proved to be very upsetting for the families of these young people. After days of close and intense monitoring following the accident, and sometimes one or more operations carried out in the first few days, the parents suddenly find themselves in an environment which appears to pay little attention to their son or daughter, and sometimes staffed by people with little specialised knowledge of head injury.

There was a total lack of care after he had come out of intensive care that morning, and we were absolutely frantic. They'd been taking temperatures and everything every half an hour or so, and then, bang! It was about 8 o'clock in the morning until teatime ... he was just laying there, they did nothing until about 6 o'clock at night - no drugs, no nothing, and he'd been on all this intensive care, he just seemed to be abandoned.

Some young people were later transferred to specialist rehabilitation wards for some weeks or months. Most parents praised the work of the physiotherapists, occupational therapists and speech therapists to return their son or daughter to normal life.

He was in there three months and those nurses ... they taught him to use his waterworks, his bowels, to sit up ... they taught him to walk, to balance - they taught that boy everything again, because he was a nothing.

Life at home

Many problems arise when the young person returns home to live with his or her family. The young people themselves have to confront such things as memory loss, poor concentration, feelings of anger,

mood swings, lack of confidence, physical difficulties, speech problems and fears about the future. These will affect them directly and the people around them indirectly. Most parents felt that once they had their son or daughter back at home they were left very much on their own. Even the provision of such things as physiotherapy and speech therapy for those who were the most physically affected tended to tail off although the need clearly remained.

The injured person's emotional lability and feelings of anger and frustration frequently cause hostility between members of the family. At the same time, parents and siblings often feel that they are "walking on eggshells" much of the time in order to avoid trouble. Many parents feel that their son or daughter would benefit from talking to a trained counsellor or, at the very least, to someone outside the family, but this service was seldom available.

He needs counselling, I think he's bloody angry ... it really, really gets to me that he is just left to get on with it, I mean, yes, it's fine for the doctors to say he's doing exceptionally well and boost his morale that way ... he needs practical help, not sympathy ... he's angry, he's frustrated, he's impatient. He really needs to get all of that out of his system, so it would help him to cope.

In most cases the parents who are trying to deal with this anger, and who are having to confront a child who has changed in many ways from the child they had before, also feel the lack of someone to talk to.

[To the researcher] Come back whenever you like, you're very welcome, because actually it's good for us to talk to somebody, to get it out of one's system ... I think I would have liked somebody like you right from the word go. Somebody who is not involved in it ... we'd have been able to take a rational view then - we were quite irrational really at times.

Almost always, the families are operating on odd bits of information culled from various different professionals, usually at an early stage and often quite useless as guidelines.

He was told by the doctor that he has got less brain cells so he really shouldn't drink like a normal person.

They also have no way of knowing whether information that was given to them a year ago, or more, is still relevant or not, or whether the labels that were stuck on then still apply - or in fact ever did apply - or even what they actually mean.

He's never been back to the neurologist... The day we left the hospital I said to the doctor "is there anything that we should be doing?" you know, we were worried, we've never come across head injuries before ... we didn't know whether he still had the clot, what had happened or nothing, they never explained anything to us - and he said, "no, nothing". You know, goodbye and good luck, nothing ... when he first came home I was frightened more than anything, we didn't really know much about head injuries, nobody ever really sat down and explained what would happen when he left hospital - to this day we've not been told anything although it's been two years, you know, you still worry all the time.

With little or no guidance about how they should proceed, parents remain highly protective of their children. This protectiveness is often seen by the young people as unnecessary restrictiveness which is preventing them getting back to what they perceive to be a normal life - by whatever means they feel they can achieve it.

I didn't give a shit if [taking drugs] was advisable or not. I just wanted to get back to normal. I didn't care what I took. You don't realise that that's the thing.

When parents, or the young people themselves, feel that they need some professional help, the response to their pleas is in many cases very slow, or even non-existent.

I don't know if you've ever tried to contact [the consultant], but it's absolutely useless. When we had all those problems, when we really did need some advice, we left message after message after message and nothing happened ... and this time because of [another crisis] we were very worried ... we phoned and we wrote letters and we still haven't had a reply.

For a number of families, it is the local Headway (The National Head Injuries Association) Centre that has proved to be the most approachable and valuable source of reliable advice and support.

The individuals and families who appear to be in the most urgent need of practical help and advice are those who not only seem to have poor rapport with the professionals, but also feel powerless in relationship to the society in which they live.

Nobody seems to bother about you ... it seems like they didn't care two hoots. I just don't think society really cares about people like [us] anyway. Now I just think, well, we must just look after each other, you

know, nobody else don't care ... you don't get any help from nobody, nobody don't bother. They say, "oh yes we'll do this, we'll help you," but they don't. It sort of goes in here and out the other side. It's a waste of time.

Relationships with brothers and sisters are often seriously affected. The necessary renegotiation of the relationships is often fraught, and in most cases the bond is less close than before. At the same time many of the young people find that by the time they leave hospital most of their old friends have dropped away, thus depriving them of a familiar social world outside the family.

The anxieties and problems that many of these young people and their families experience are still apparent after a few years, and show no signs of disappearing. Although life at home may run smoothly for a time, new problems often crop up, or old ones reappear.

It's so unfair. It's almost like having a prison sentence, but not being imprisoned ... it's the fear of the unknown, you think you're going along fine and then something comes up and you think, oh my God, back to square one, and it's that constant sort of stop and start that really plays havoc with you, I mean it does me, particularly now - not at first, I was strong enough to cope then - but it's really wearing me down now. And the longer it goes on the worse it gets.

Some parents, when the trauma of the accident and its immediate aftermath have passed, resent the return to parental caring roles at a time when they were just beginning, as their children left home, to live their own lives again.

Work

Only three of the twenty young people had returned to a similar life situation as before (one to a job, two as students). Six were in workshops or day centres for people with disabilities, two in part-time (unpaid) employment. Of the remaining nine, four had returned to their old jobs, or apprenticeships, but these had not continued. Although employers may have had best intentions, their lack of knowledge about the effects of head injury, and an apparent lack of flexibility meant that raised hopes were soon dashed.

They haven't taken Craig back [on the payroll]. They keep telling me there's nothing wrong with his work, he does his job well, they're pleased with what he does. Now that boy is working apparently full time

there, and is still on £51 a week benefit, I feel they're using him ... that boy is getting so screwed up and frustrated now, because he's written down all the hours that he's done for them for nothing, it's about 900 hours.

The lack of success that many of the young people experience in their attempts to return to work further increases their sense of social isolation.

About the study

This was an intensive anthropological study of twenty families in which there was a young person who had recently suffered a severe head injury. The young people were aged between 16 and 25. The families were visited a number of times, over more than a year, in order to document their daily lives, their sources of help and advice and the nature of their interrelationships.

Further information

A full report of this study, *Life After Head Injury: The experiences of twenty young people and their families*, is published by Avebury. For further details contact Customer Services, Avebury, Ashgate Publishing Ltd, Gower House, Croft Road, Aldershot GU11 3HR.

For further information about the research, contact Jane Hubert, Senior Research Fellow, Department of Psychology, University of Southampton, Southampton SO17 1BF.

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