

LEARNING ABOUT HEAD INJURY: A PERSONAL ACCOUNT

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The authors were invited to submit this article to highlight the needs of patients and their families when a brain injury has occurred. They are trained professionals who have made a transition from near-ignorance to deep knowledge and experience in one specific area of patient care, a painful and continuing series of events occurring within their family and an important topic for other doctors to understand.

It is, by its nature, a personal account that reveals much about a named patient, their son Ben. He has given his consent to the publication of this article.

Nothing can prepare you for the knock on the door at 2am and a local policeman framed in the door. "Your son Ben is in Intensive Care. All I know is he's unconscious". Those of you with teenagers will probably have speculated on the scenario, but the reality is that it's as bad as you think, and then far worse.

Our youngest son, Ben, was injured in a car accident almost two years ago. He suffered a severe closed head injury in addition to multiple orthopaedic injuries. He required artificial ventilation for three days and CT scans indicated cerebral contusions. He suffered from a period of post-traumatic amnesia of about three weeks' duration after regaining consciousness, which indicates a severe head injury. At that point we didn't know the extent of the brain damage. The doctors kept us informed at every stage and were optimistic that he would survive, but were guarded in their prognosis. Initially we just wanted him to live, no matter what. After he recovered consciousness and was showing signs of cerebral dysfunction we wanted to see improvement every day, as we knew the possible outcomes. This didn't happen. The fact that we are doctor and nurse had very little bearing on our feelings and behaviour whilst Ben was in the ICU. The staff may tell a different tale. We were treated at all times as 'parents'. This was so important to us and we acknowledge the amazing skills of the nurses and doctors who achieved this. Nurses and doctors are not renowned for making the best relatives.

We were referred to Pen Hutchinson (Acquired Brain Damage Coordinator, Lancaster Priority Trust) by the nurse manager of Ward 7. Ben's uninhibited and challenging behaviour was taxing everyone involved in his care and we needed some guidance. We were feeling extremely exhausted at this stage - we didn't know how to handle Ben's restlessness, agitation and obvious distress. We felt guilty that he was obviously disturbing the other patients and I suppose we felt angry that we didn't appear to be getting the support of the staff. Pen came to see us on the ward, explained to us the reasons for Ben's present state, explained that this was all normal in the immediate post-head injury period, and that

there were things we could implement so that we didn't exacerbate the situation and make him more distressed and aggressive. Simple things like giving him a white board so we could write the date on for him. When we left him at any time we could write down where we had gone and when we would be back. We needed constantly to remind him of where he was and why, and to explain about the plasters on his arm and leg. As he could not always remember who he was we brought photographs of the family, his home, his bedroom and his personal possessions, in an attempt to give him back his identity.

Even with the best will in the world we would never have worked things out for ourselves. We were feeling hopeless and helpless by this stage. We had attended two funerals of Ben's friends that week and we needed direction. Pen gave us that and put us back in control. She was unable to follow us up at home as we live in Cumbria and she only covers the Lancaster NHS Trust. But she was always available on the telephone to provide practical help and support, which was badly needed. She put us in touch with the local branch of Headway (National Head Injuries Association) and gave us their booklets, which proved to be invaluable.

Pen suggested that we consider the possibility of contacting a solicitor to pursue a compensation claim. We hadn't even considered this. It was early days: we were thankful he was alive. She left us in no doubt that this was the course we should follow and we are so glad we took her advice. A contact from the local branch of Headway advised us to choose a solicitor who deals only with head injuries. Pursuing a compensation claim has provided access to aftercare for Ben that has not been available on the NHS. This is not meant as a criticism, just a statement of fact. Apart from our contact with Pen, Ben has had no follow-up care regarding his head injury, and yet that is the injury that has left him with the most problems. He continues with excellent care from the orthopaedic department.

The compensation claim will take five years or so to complete. The interventions of care financed by the insurance company will reduce the final settlement as hopefully Ben will have fulfilled his educational and emotional potential and will be in employment.

The opportunity to be assessed every six months by professionals in this specialised area (neurologists, neuropsychologists and occupational therapists) has highlighted for us the extent of his problems, the subtleties of his disability and the difficulties he will have to face to move on. Friends and relatives feel that he is just as he was before, but the changes are hard to discern and Ben has developed skills to mask them. He returned to college three months after the accident but gave up after two months because "everybody seemed to know what they were doing and he

knew nothing". Since then he has attended college part-time to attain a language qualification and works in a cafe here in Kirkby Lonsdale, preparing and serving food – a job he had done four years earlier when he was at school. He needs to move on, but is finding it difficult to take the plunge. It is important that he is not set up to fail. Due to the particular vulnerability of the frontal lobes of the brain he has problems with executive functioning, judgement and decision-making. He tends to jump to the wrong conclusions and over-reacts. He is never sure when to speak out or to keep silent.

His ability to think in the abstract is impaired and he is unable to interpret proverbs such as 'a stitch in time saves nine'. He suffers from aboulia, a lack of motivation, initiative and drive (not to be confused with laziness). He has only partial insight into his impairments. His current lifestyle, living at home and working in the protective and supportive environment of Kirkby Lonsdale, masks and makes allowances for his problems. He copes with his cognitive and emotional difficulties through avoidance and denial. Having said that, he is always cheerful, never depressed and never feels sorry for himself. He's glad he survived.

It has been recommended that he embarks on a rehabilitation programme to teach him strategies to compensate for his poor executive functioning. He is waiting for a place at the Transitional Rehabilitation Unit at Haydock. This is an intensive programme not available on the NHS. He could be residential, but he will probably go for three days a week for three months.

You may ask why is follow-up so poor in the NHS? Who knows: maybe it's because the majority of head injuries are

acquired in accidents where somebody can be seen as liable and insurance companies then come into the picture. Most of the professionals involved are employed in the private sector. But what about those for whom insurance doesn't provide cover.

Health professionals, including GPs, know very little about the aftercare of people following head injury. This needs to be addressed through education, but if that's impossible (as we suspect it is in the present climate) then more resources should be put into posts such as Pen's. They hold the key to aftercare. We know that since Pen has been in post she has achieved a great deal in educating and increasing awareness of the issues surrounding the recovery and rehabilitation of people with acquired brain injury

This has been a difficult article to write, but we would like to thank the editor for tentatively suggesting that we might put pen to paper. It has been a hard two years for Ben and it is not going to get any easier for a long time, but with his sense of humour and resourcefulness he will get there. His positive attitude has made our role as parents so much easier and we are grateful to him for that. The hardest and worst part for Ben has been coping with the loss of his best and lifelong friend Edward. They had been best friends since playgroup days and had been inseparable ever since. He misses him dreadfully, as we do.

Our solicitor said to us at our first meeting "You are going to be responsible for Ben for a lot longer than you think". His words have stayed with us and are proving to be true. But how thankful we are to have the opportunity.