



## **The Family following Acquired Brain Injury**

It is said that coping when a family member suffers acquired brain injury can be one of the most difficult tasks which can confront a family. The family may face uncertainty in the initial period following the head injury, even to the point of having to prepare for the fact that the family member may not survive. Recent advances in medical expertise mean an individual with acquired brain injury is now more likely to survive. However, there may follow a long period of rehabilitation before they can return home.

Whereas in the early stages the family had to face an uncertain future, as time goes by they may have to come to terms with the dramatic changes that acquired brain injury can cause. Parents, siblings and children may have to cope with considerable changes of personality and behaviour. Some of the most distressing changes can involve aggression, sudden changes in mood, a self-centredness, impulsivity, sexual and social disinhibition, poor motivation and lack of empathy. These changes can be awkward and embarrassing and friends or members of the family find them difficult and start to stay away when support is most needed. In this way the immediate family as well as the individual with the brain injury can become increasingly isolated. It is now clearly recognised that the pressures upon the family can become intense if not intolerable.

Many research studies conducted in recent times have documented the significant pressures which are placed upon families of those with traumatic brain injury. They generally have to provide long-term support, social outlets and direct assistance to the injured person. Relatives' distress can remain high for many years. Anxiety and depression is evident in at least 25-30% of relatives and 60 to 80% report some degree of emotional distress. Reported rates of marital breakdown more than five years following a severe traumatic brain injury range from 78% in those with very severe disabilities to 42% in those with a "good" outcome.

Among the most commonly documented sources of difficulty for families of individuals with a brain injury are changes in emotional control, and personality or behaviour, particularly irritability and aggression, and cognitive difficulties such as slowness and memory problems. Researchers have found that the stress caused by these problems does not necessarily reduce over time.

Sometimes there is little social and practical support in caring for the injured person. Many family members have to take up new roles, for example, a wife having to take over the financial management of the family. The individual with an acquired brain injury is often left with problems that will not allow them to resume their normal role within the family and within their wider society. It will be clear from the type of problems seen following acquired brain injury that emotional interaction can be difficult. Difficulties in expressing oneself can limit communication with friends and family. It is often the case that sexual functioning can be affected by acquired brain injury. Such changes in sexuality can take different forms, for example, there may be a reduced sexual drive (hyposexuality) or an increased sexual drive (hypersexuality), the former being much more common. Such problems may not be recognised, particularly where individuals are uncomfortable with discussing such matters with professionals.

It will be recognised that the partner of someone with acquired brain injury requires a strong support network and time for relaxation to look after their own well-being.

The children within the family have their own particular distress. They may have effectively lost a parent with whom they had a very close relationship. Children need a sense of security derived from the consistency of parenting, but people with brain injury can become extremely inconsistent. Children may feel embarrassed by the behavioural changes in one of their parents, and may be reluctant to bring friends home in case their embarrassment is compounded. It is important for children to understand the nature of brain injury, as far as is possible given their level of intellectual and emotional development.

The Rehabilitation Team involved in early rehabilitation input can help the family make adjustments to the individual with a brain injury particularly finding ways for them to take on a fulfilling role. They can provide assistance and support with regard to communication, and can give advice concerning the management of behavioural problems that may arise. The team may offer emotional support to family members who find this adjustment particularly difficult.

The Rehabilitation Team will make every effort to help the family accept the brain injured individual, although the high risk of emotional reaction within family members indicates that some degree of psychological support will be required. Research suggests that the presence of cognitive, behavioural and emotional changes is the strongest predictor of anxiety and depression in relatives, and of unhealthy family functioning. While it is reasonable that every attempt should be made to provide long-term support and care to alleviate the stresses on relatives, it may sometimes be necessary for the Rehabilitation Team to help the family accept that clinically caring for their family member may not be in anyone's best interests. Naturally, having to accept this idea may be extremely distressing, in the short term, at least.

The majority of individuals with acquired brain injury return to the care of their family, and consequently families bear the brunt of the emotional and behavioural changes which can follow brain injury, often in the absence of appropriate information or advice. Not surprisingly, many family care givers report high levels of distress and depression as they attempt to cope with these problems. The Brain Injury Rehabilitation Trust recognises the need for family support as part of its continuum of rehabilitation and care. Researchers suggest that possible factors leading to better adjustment include clear personal expectations, seeing positives among the negatives, dwelling on those aspects of the individual with brain injury that remain the same, the desire to master the situation, strong motivation, flexibility to adjust life goals and, the possible need to accept that in many cases the family may be unable to bring about the major changes in the individual with acquired brain injury that they would wish.

Different individuals cope with brain injury in different ways. Men and women often cope differently. Women actively seek social and emotional support, while men may isolate themselves. Women may be more involved in direct caring whereas men may attempt to organise services for their injured relative. Some people find support groups, counselling and education about brain injury helpful whereas others feel they spend enough time thinking about brain injury and choose to spend any spare time on entirely unconnected pursuits. There is no "right" way, whatever the individual finds helpful is right for that individual.



In our Units we try to offer a range of options that family members may find helpful but do not want relatives to feel obliged to participate in any of these. We understand that they be helpful for some but not for others. Perhaps the one thing that is most helpful for relatives is information about brain injury and its ramifications. Even here there can be a right place and time to receive information and this series of pamphlets is designed to provide some help in this respect. If you have read this far, we hope you have found it useful!

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