

Changes in relationships for families and couples after brain injury

The impact of a brain injury has often been likened to throwing a pebble in a pond—the influences go far beyond just the person who has acquired the injury, including partners, friends, family, caregivers and work colleagues. The issues and needs of partners and family members will vary according to the stages of the recovery process. Each stage will bring its own joys, challenges, hopes and needs. Old coping methods may remain helpful for some; for others, new methods will need to be developed. Resentment, anger, despair, grief and numbness may be emotions encountered. Your task in the process of recovery is to sort out what you are feeling, and seek out help and support for yourself.

Acute stage

In the acute stage, the physical trauma to your loved one is often life threatening. No one wants to leave the hospital; everyone's focus is on the patient. Your focus at this time is on your loved one who has been injured; your own needs right now hardly seem to matter. Your friends want to help; this is the time to let them. The rest of your "outside-of-the-hospital" life still needs tending to, and your friends can relieve that worry by taking care of the house, children, car pooling, shopping, and so forth. Beyond attending to day-to-day tasks, some may want to offer emotional support as well. You may have conflicting feelings about this. Your good friends will understand and be there for your needs, whatever they are. You might find it helpful to name one or two of them as coordinators. They can return phone calls for you, offer apologies and thanks to others, and do whatever else needs to be done.

Post-acute stage

In the post-acute stage, the patient is medically safe and has been moved to a rehabilitation center. At this point, you can relax a bit and start to put order back into your world outside of the hospital. Part of this may include offering multiple thank you's to your friends. You may feel exhausted and out-of-sorts. This is part of the natural letdown of the initial trauma, a time when you realize that you have been (and are) tired and worried. You may not feel like talking to, or being with, your friends right now. You may be pre-occupied by your own concerns. You may not want to talk constantly about the injury and burden your friends, but you don't really want to talk about anything else, either.

You may want to be with your friends – but then won't want to. This is a perfectly natural reaction even if it feels disconcerting to you. Ask your friends for their patience and grant yourself the same. You may find more comfort being with other families in the rehabilitation unit who are going through what you are, than being with your old friends. Take advantage of the support if it is what you need.

Community re-entry stage

In the community re-entry phase, the person with a brain injury moves back into family life and begins to renegotiate his or her social world. You, as caregiver, begin to redefine your world as well.

When a loved one returns home everything initially readjusts around that person. Your friendship needs will change again. You will find it difficult to leave your loved one and go out. You may want a friend or two to visit, but even that may feel like it is too much, because of the extra work that now goes on in your world. Some friends may be comfortable with what has happened, and with the difference they observe in your loved one – and perhaps in you. One of the first ways to address their fears or discomforts may be to educate these friends about the injury. With information, they can become more comfortable with the situation.

Many of you at this stage will find yourselves feeling anger and resentment at your friends' happiness. You may feel isolated, with no way to share these feelings with old friends. You may wish to seek out support groups of other caregivers, who are feeling just as you are; these groups can provide a good social support. Above all, remember that it is time now to give your own needs priority. You do need to go out, to take time for yourself.

IN THE LONG TERM

Family

One of the common issues that families face is their son or daughter with an injury returning to the family home despite having lived away from home prior to the injury. For the person with the injury this can represent a huge loss of independence and self-reliance. For the family, they now have someone who is either fully dependent or semi-independent. Family members' lives can change significantly. Their future plans may be put on hold to take care of their loved one. They often have to cope with dramatic personality and behavioral changes. Some of the most distressing changes can involve aggression, rapid changes in mood, self-centeredness, impulsivity, sexual and social disinhibition, poor motivation and lack of empathy. Friends of the family often distance themselves over time and become quiet bitter unless they have a good understanding about why this behavior occurs.

Partners

The rate of marital and relationship breakdown is very high following brain injury. The pressures on a spouse or partner can be immense. They may have to take over the running of the house, become the sole wage earner, increase or decrease their hours of work, make most of the decisions and provide support to the person with the injury. Finances may become a major concern due to medical bills and loss of income. A change in the sexual relationship of a couple can also be a very distressing and sensitive issue. These changes may involve either a reduced sexual drive (hyposexuality) or increased sexual drive (hypersexuality).

Children

The person with the injury may have had children before or after their accident or illness. From a child's point of view it is often more difficult to have known their parent before the injury. In this situation the child has to come to terms with why their parent has changed so dramatically after coming home from hospital. After the accident it can be extremely difficult for a child to understand why their parent needs care, walks or talks strangely, never remembers anything, gets upset so easily and why they no longer want to play with them.

Children may display increased acting-out behaviors, emotional problems, or relationship difficulties. Negative parenting performance such as yelling, ignoring or being impatient by both injured and uninjured parents is reported in most families. Most families report substantial breakdowns in relationships between children and their injured parent when it is the father who is injured. Most non-injured parents report substantial depression, which correlated significantly with negative behavior in children.

Friends

A very common statement made by people with brain injury is 'you find out who your real friends are' after the accident. Unfortunately, friends can disappear at the time when the person most needs their support. It is also common for people who have spent a long time in hospital to feel that they have missed out on a lot of experiences with their friends and that they now have trouble relating to their friends and sharing their interests.

Supportive friends learn to adjust their expectations of the person with the injury and seek new activities for spending time together e.g. watching a game of sport instead of going to a nightclub. Alternatively, the person may wish to meet other people with a brain injury by joining a specialized group rehabilitation program or a less structured brain injury social group.

MAJOR ISSUES FOR COUPLES

Both men and women with brain injuries find the loss of autonomy and independence is their biggest problem, and both mention personality changes and memory deficits as significant. Among married couples, wives identify their brain-injured husbands' personality changes and cognitive deficits as primary problems. Husbands, by contrast, place their brain injured wives' loss of autonomy and mood

swings at the top of their lists. Families in which husbands had sustained brain injuries place higher importance on job loss and income change than do families in which wives were injured. Women with brain injuries and non-disabled wives value support groups and other emotional support methods as coping strategies, whereas the men stressed problem-focused and goal-orientated strategies. Brain injured individuals with higher ratings of cognitive and social dysfunction are more likely to be depressed and anxious. Non-injured spouses also show increased anxiety and depression, with wives more affected than husbands.

The information above is from a fact sheet on brain injury available at www.biaq.com.au/facts.htm reprinted with the permission of Brain Injury Association of Queensland and provided here by the Brain Injury Association of Virginia (BIAV).

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The following is an excerpt from the website of Headway - the brain injury association [of the UK]: www.headway.org.uk

LIVING WITH BRAIN INJURY: FAMILY ISSUES

Families need attention, education, guidance and support if they are to survive, regroup and rebuild their lives. Some families cope better than others, but all have difficulties. There is no normal way of responding to a head injury. The saying that 'people act abnormally in abnormal situations' is undoubtedly appropriate.

The people in families and relationships who seem to cope best are those who have two special qualities. Firstly, they have the ability to be flexible, not being rigidly tied to how things ought to be but being able to embrace change and view it as a challenge. Secondly, they have the ability to communicate openly and honestly, directly expressing emotions both positive and negative and recognizing the needs of themselves and others within the family. If a family has these characteristics of flexibility and open communication, then it is possible that, out of the crisis of head injury, a family can grow in strength through its way of dealing with it. The fragility of life can give a whole new perspective and intensity to the love that existed prior to the head injury. Having a person with disability in the family often brings a new sensitivity and awareness to other members of the family. It is often said that the experience of head injury tends to make strong marriages and relationships stronger and troubled relationships more troubled.

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For more information about brain injury or services and resources in Virginia, please contact the Brain Injury Association of Virginia (BIAV):

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