

My Adult Child has an ABI

Acquired Brain Injury (ABI) can be a devastating experience for the parents of an injured adult child. Parents say they have had no time to prepare for the many changes that occur to their lives as a result of their son/daughter's brain injury. Often, now that their family have grown, parents are at the stage of planning for their own future. It seems that life and those plans disappear in an instant.



Changes in personality and behaviour of their child, as the result of the injury, can be very disconcerting for parents. Displays of childish behaviour can be embarrassing, while mood swings and having to provide guidance and feedback can be challenging.

Possible Reactions

In coming to terms with the fact that their son/daughter has sustained a brain injury, parents, like all family members, experience many emotions. These could include:

- Shock and denial – at the immediacy and severity of the injury and the consequences of brain injury / changes to your child
- Anger and frustration – at the circumstances of the injury, of how it has impacted on your life and how your child's life will change
- Loss – changes to plans, financial losses, grieving the loss of the future parents had anticipated for themselves and their children
- Resentment and guilt – resenting the changes, feeling that you could have “done something better”, feeling guilty for feelings of anger, resentment and frustration
- Loneliness and Isolation – many parents report the gradual withdrawal of their friends as their lives have now taken different directions with different priorities.
- Some parents say that they have lost interest in things they used to enjoy.
- Mourning/Chronic Sorrow – Grieving processes rarely end, as a loved one remains in your life, but often as an altered person. It is common to mourn the personality and characteristics that have been lost while learning to relate to a different person. Mourning is never completed but can begin again with reminders of what has been lost.

Relationship and Role Changes

Depending on the severity and nature of the ABI, *relationships with their son/daughter could have changed* in several ways:

- ABI places a strain on many relationships and marriages. Concern about a child's relationships, practical issues of how to help, and uncertainty about how the situation will work out is common.
- Tensions between parents themselves can manifest. Different attitudes and expectations and different ways of coping can aggravate this.
- Becoming a carer – it is possible that the injured adult may move back home. If this involves basic personal care and cueing with daily living tasks, it may be like parenting a child all over again and the relationship is no longer an adult relationship. This can be especially difficult if the ABI has resulted in challenging behavioural problems.
- Having carers or lifestyle support workers coming into the home on a regular basis can place a strain on relationships as parents feel that their lives are less private.
- Help with grandchildren may be needed when one parent has an ABI and the other is committed to a significant caring role or full-time employment.
- Parents often worry about how the ABI has affected their relationships with their other children. Some parents find themselves being more over protective of their other children; some worry that they are neglecting their other children and feel their resources (emotional, financial, time) are stretched in this regard.

- Relationships with friends and extended family may also change especially if parents feel that others do not understand the ABI.

Many parents find that *roles in the family change* as a result of their adult child sustaining a brain injury:

- Parents may have to take on a carer role with their adult son/daughter.
- Previously valued roles may change e.g. giving up work to be a carer, loss of retirement plans.
- Grandparents may become more involved in their child's own family as a result of the brain injury and may even take on the parenting role with their grandchildren.
- Parents may need to take on a more supportive role in relation to the spouse of their son/daughter.
- Parents may need to help educate and support other family members and friends about brain injury.

Practical Consequences of ABI

There may be many practical consequences of the brain injury. Parents may find that they need to be involved in provision of:

- Accommodation or sourcing alternative accommodation for their son/daughter.
- 'Hands on' assistance for their son/daughter e.g. feeding, bathing, supervision, etc.
- Transport to appointments and community activities and attending appointments with their son/daughter.
- Assistance for their son/daughter with managing finances and making decisions. This may involve applying for Centrelink benefits. Parents may find this difficult as it may never have been necessary before the injury.
- Assisting their child to maintain pre-existing relationships
- Social support and social outings for their son/daughter.
- The need to ask other family members or services to assist their son/daughter.
- An increase in the amount of time that parents spend with their child or child's families.
- The effects of the loss of income when the injured person was the primary income earner. This may result in an inability to meet previous financial commitments such as mortgage repayments, car payments, childcare or children's school-fees.

At times an ABI will result in challenging behaviour which requires understanding of the reasons for the behaviour and strategies to manage the behaviour. Professional assistance may be required in some cases.

Useful Strategies

Some strategies to help coping are:

- Becoming involved in the hospitalisation and rehabilitation stages.
- Learning as much as possible about the brain injury to assist developing realistic expectations
- Realistically considering the strengths of individual family members.
- Identifying areas where assistance would be beneficial and asking for help.
- Talking about concerns with other family members/friends.
- Taking time to deal with the effects of the injury.
- Keeping daily routines as normal as possible.
- Being open to involvement in support groups and counselling.
- Spending quality time with other family members.
- Encouraging the person with ABI to gain as much independence as possible as it is important to allow them to learn new skills and to be as independent as possible. Be guided by the professionals working with them.
- Remember that a brain injury does not change everything about a person and some personality traits, behaviour traits and interests will remain unchanged.

- Developing and maintaining a good network of friends and activities to avoid becoming isolated.
- Being just as aware of the things the person with the ABI can do, as you are of the things they have difficulty with.
- Using supports such as regular respite when needed.
- Take the time to rest, rejuvenate, and care for yourself

Further information can also be obtained from the Synapse website (Formerly the Brain Injury Association of Queensland).

<http://synapse.org.au/>

Contact ABIOS

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