

Reactions and responses to a child's brain injury

Brain injury in a child causes many different reactions in the family. There is no single, predictable pattern but the ongoing emotional stress can be very difficult.

Feelings change over time, and finding ways for everyone to adjust and get back on an even keel can take a long time. It can be confusing, chaotic, and difficult at times to work out exactly what you are feeling. Relationships within the family may change. Sometimes people see a pattern in their lives, but often there just seems to be constant stress.

Often, the first reaction is shock and disbelief, particularly if the brain injury is sudden and obvious. On the other hand, a diagnosis of brain injury may be a step forward, if you have been concerned for some time about unexplained problems for your child. An explanation may help you to move on and focus on finding the best ways to address the problems.

Gradually, families adjust to what is happening, and become more aware of the implications and the effects on everyone's lives. Some may search far and wide for a cure or a treatment, others rest their faith in the treatment team and concentrate their efforts on simply getting back on track.

Rebuilding hope

It takes time to realize that, although everything won't return to the way it was, there are positive ways of adapting and coping, and good things ahead. But parents who have lived for a long time with the changes a traumatic brain injury or similar brain disorder produces know that things can get better.

Their messages of hope for people just beginning this journey include:

- You haven't failed, even though you may feel you never do enough
- It's possible to work with negative responses in positive ways
- Grief doesn't necessarily go away, but over time, it becomes possible to see things from a new and positive perspective.
- All the many different and conflicting emotions you may feel are normal
- Let yourself grow gradually into your own situation
- Find people you can talk to - friends, your partner, family, support groups, people in your community.
- Remember that, first and foremost, you are a mum or dad, even when you're doing the work of an occupational therapist, speech therapist, physiotherapist or counsellor.
- Ask for help, and if you don't get it, ask again and again.

Professional help

Many people have found professional help from a psychologist or social worker can provide a positive pathway through these emotions. It can help to prevent difficult emotional patterns from becoming entrenched, and can also help you to keep family relationships on track.

If you or one of your family members is struggling with these emotions, consult a mental health professional about appropriate treatment, including medication. Look for a therapist - a psychiatrist or clinical psychologist - who has experience dealing with carers. If medication is needed, it can be prescribed only by a medical practitioner (a psychiatrist or GP).



If mental health professionals are in short supply in your area (for example, in some rural and remote areas), find another health professional in your community whom you trust and can talk to. Social workers are trained to provide families with considerable support, both emotional and practical. Some GPs are very good in this role, and therapists and community nurses also provide emotional support as part of their work.

Positive way to work through negative emotions

A child's traumatic brain injury is often a devastating event for parents and families. Everyone reacts differently, but parents and families often feel guilt, grief, hopelessness and despair, a sense that the difficulties will never end. Everyone else may seem to know better and have advice for you - often when things are at their most difficult. All these feelings are common and normal - but they don't help you to cope.

Guilt

When someone has a brain injury, other family members often feel guilty in one way or another. This feeling is common, but you need to work through it if you are going to get on with your life productively. The first step is to accept that guilt is normal, and that you can't stop it appearing - you don't need to feel guilty about feeling guilty!

Look carefully at your guilt - how realistic is it? If there is something you really could have changed, try to forgive yourself for not doing it, focus on what you can do now, and move on. If there was nothing you could have changed, recognize that your guilt has no basis in fact. In either case, you'll need time to deal with feelings. Talk to a good friend or consider finding support through a counsellor, for example, at the local Community Health Centre.

Grief

Grief and anguish are normal, though everyone experiences them differently. It can be a real struggle to adjust to these losses and changed expectations - but there are many positive things you can do.

Acknowledge and accept what has happened, and look ahead. Try to treat your child as you always have done - don't let yourself turn your child into someone different, a 'patient'. Retain what you can of the good things you used to have together. Talk to other mums and dads of children with disabilities.

Be kind to yourself. There will be sad moments, but good times are possible, too. Arrange for your child to do different special things when other kids are passing 'normal' milestones (e.g. going to university, getting married).

Hopelessness

Parents can feel despair and hopelessness - particularly when recovery slows down - as they realize life will never return to its former pattern. These suggestions may provide a starting point to help you work through this despair:

- Don't put arbitrary time limits on your child's recovery - that sets you up for disappointment (even if organizations act as if there are time limits).
- Be ready to modify your hopes and expectations. A young person with a brain injury may not return to their pre-injury self, but they can be happy and achieve in other ways. Take this as your starting point.
- Focus on the things your child can do, rather than dwelling on what they can't do as well as before.
- Find ways to see, and to celebrate, the good things in your child's life. For example, some families find it helps to sit down together regularly (e.g. monthly) to review what's been achieved, celebrate the good things, and set more goals.
- Consider finding support from a professional (psychologist, social worker, etc.) to help work through emotional issues - and consider doing this early on, before problems become entrenched.



Blame or criticism

Sometimes, it can seem that everyone knows better than you. Family, friends, even people who have little contact with your child, give you advice, pass judgement, or tell you what to do - particularly when things aren't going well. You have less privacy, and everyone is an expert except you.

Such criticisms and remarks may stem from the person's own feelings of frustration and powerlessness in the face of your child's injury - particularly if the person is close to your child. Understanding this may help you to cope better with the comments. If criticism comes from someone close to you, consider talking openly to that person about the impact on you.

It's also worth listening to comments to see whether they include anything that is actually helpful - even if you feel hurt. It's not wrong to get frustrated or 'lose your cool'. But you may feel better about yourself and more in control of the situation if you can learn how to manage and express your feelings in ways that don't damage relationships and friendships.

Remind yourself of the positive things you are doing and achieving. You might, for example, make a list and stick it on the fridge door, of "good things we've done this week".

Look after yourself

An injured child can place enormous strain on parents. Sometimes the relationship becomes stronger, but couples can also drift apart.

Some things that put strain on relationships are a sense that one or other of you is to blame, differences of opinion about how to handle specific issues and differing views on how family life should change in response to the injured child.

Open communication between a couple (even if they're separated), supportive friendships and the right professional help can all assist. Opportunities to talk to others-and cry-in safe, confidential surroundings give many parents the strength to carry on.

Assistance from carer respite services or disability services can be vital, especially for single parent families.

Keeping in touch with friends

When the young person comes home, family members often focus on providing a quiet environment and emotional support, and see less of people outside the home. It's easy to establish a pattern where life revolves around the child with a brain injury.

Some friends may offer great strength and support. Others may drift away. This can be hurtful, but it usually happens because they can't cope with the situation in some way.

Here are some suggestions to consider:

- Let friends and family know they matter to you
- Let them know how they can support you - for example, doing the washing, baby-sitting other children, coming to an appointment with you, or just having a coffee together
- Try to talk about issues other than your child and brain injury
- Schedule family outings or social activities even if you don't feel like it
- Don't think you're the only one who can care for your child
- Involve extended family and close friends in the 'team'.

Ask for professional help in dealing with emotional upheaval. If there are waiting lists for public services, consider seeking help privately if you can afford it (Medicare often will cover some of these expenses).

References and further information

Many thanks to Brain Foundation Victoria for permission to adapt their material for this fact sheet.