

# The early days after your child's brain injury

**Raising a child brings challenges to all parents, and for parents of a child with a brain injury, those challenges can be magnified.**

## In this article

- Parenting a child with brain injury
- Will my child be okay?
- Things you can do
- Looking after yourself
- Should my child be assessed?

## Parenting a child with brain injury

There are many issues to consider when parenting a child with a brain injury. Striking a balance between protecting them from harm while encouraging self-reliance and independence can be difficult. It may not be clear in the early stages, what problems a traumatic brain injury has caused, and it can be difficult to predict how much a child will recover, and how fast.

It is easy to focus on the differences - how your situation is different to other families with children. But in general, most parents face a very similar range of challenges. Aim to focus on these similarities and claim your place, and your child's place, as part of your local community.

At times the emotional challenges can seem overwhelming. Grief, in some shape or form, may always be there. Parents can feel they've lost their privacy and sense of control - everyone else has 'good advice' and knows best. You may feel isolated and 'different' from other families, or that there is no one there to help.

But many parents also say that this life-changing event has also helped them realise what's really important and value what they do have. Many families also discover they're not alone-many find that linking up with others in a similar situation provides great support. Alongside the difficulties, lots of good things happen, and families need to recognise and celebrate these. By and large, families with a child with a brain injury get on with life very competently.

## Will my child be okay?

This is the most important question for parents in the early days after a brain injury -be it either accident or serious illness. You probably won't take in much of the information you are told at this stage so get people to write things down for you.

Your child may be in a coma-not opening his/her eyes or responding in any way. Coma may last for minutes, hours, days or longer. As your child comes out of coma, he/she will move into a 'twilight' one-awake but confused, disoriented, maybe agitated, and not making sense. This is known as post-traumatic amnesia, or PTA.

In PTA, your child may remember things from the past, but won't remember things happening now, from minute to minute. Ordinary things may look strange or different, or your child may imagine things that are not there-an experience that can be frightening or confusing. Later on, your child will remember little or nothing of this time, or may have a sense of it as no more than a blurred dream.

PTA may last for minutes, days, weeks or months. The length of time in PTA provides a reasonable basis for predicting how well your child will recover. The depth of coma and how long it lasts provide another indicator.

Talk to the staff on the ward-doctors, nurses, therapy staff, and be ready for answers to change and become clearer over time.



### Things you can do

The most important thing for your child is feeling held, loved and supported by family and friends—even while in a coma. Always talk and behave as if your child is conscious— we simply do not know whether people at this stage can hear or understand anything of what is going on.

During PTA your child will be less able to deal with the amount of noise and activity around, and might easily become more agitated or restless. Try to pace interactions and inputs, so things happen at a quiet pace and only one thing at a time.

Bring in photos, doona and favourite things to create a familiar environment. Help the staff to get to know your child— his/her interests, personality, habits, quirks and talents. You may be able to do some of the day-to-day routine care for your child, if you wish to. Talk to the nursing staff about this.

As the days go past, keep a book to record what's happening. A book of this nature can be reassuring to a young person who realises, some time later, that they have 'lost' and forgotten some days or weeks of their life.

### Looking after yourself

You will need all your strength to get through this difficult period. Make sure you look after yourself while your child is in hospital (and afterwards). Make chairs into a bed to get some sleep and keep your energy up with meals at the cafeteria. If you want some quiet time, go to the hospital chapel. Accept offers of help from relatives and friends, so you can spend more time with your child and your family. Pacing yourself is still important when your child comes home from hospital. This can be a time of major readjustment for parents.

Quite apart from the physical demands of caring, changes to your child from the brain injury may suddenly become distressingly clear. Being prepared for this can help you to cope with it and continue the process of readjustment.

### Should my child be assessed?

If you are concerned about difficulties your child is having with, for example, learning, memory, speaking, balance, vision, or handwriting, such problems should always be thoroughly assessed— whether or not your child is known to have a brain injury. Careful and thorough assessment of the traumatic brain injury or other brain disorder is vital to find the best way to help your child - whatever the cause or the diagnosis.

### In the months ahead

The long-term effects of a brain injury may not be evident for some time. Some may show up only years down the track, when the child is challenged to learn increasingly complex skills and deal with more complex situations. Any of the following changes suggest the need for a thorough assessment to determine how best to help the young person:

- Difficulty with new school work or activities
- Problems in concentrating and remembering instructions
- Slowness in thinking about new things
- Less ability to join in familiar games and activities
- Difficulties understanding what's said or following a conversation
- Decreased ability to re-tell the day's events or find the right word
- Inappropriate sexual discussions or activities.



## Talking to doctors & other professionals

If you are concerned about any of these symptoms in your child, or if there is any question of a possible brain injury, tell your doctor of your concerns. The doctor will normally examine your child and may make a referral to a specialist doctor such as a neurologist, rehabilitation specialist or paediatrician. Other specialists who may be involved in assessment include a neuropsychologist, speech pathologist, physiotherapist and/or occupational therapist.

If possible, provide the doctor or specialist with the following information:

- When your child was hurt, injured or ill, and what happened
- What was done in the Emergency Department
- The name of any doctor who treated your child
- The changes you've seen in the child
- Problems your child is having in school, with friends or at home - you may need to contact teachers and get feedback from friends
- Examples of how your child seems different now
- What you do to help your child.

## References and further information

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