



Signposts

for building better behaviour

Acquired Brain Injury

Parent Notes

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Acquired Brain Injury

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How to use Acquired Brain Injury Parent Notes

The *Signposts for building better behaviour* program was designed to help families manage difficult behaviour of children with intellectual and developmental delays. While children with acquired brain injury are different in some important ways from other children, including those with other disabilities, the general principles that underpin Signposts apply to all children. By using this resource, with appropriate changes in emphasis, parents of children with acquired brain injury (ABI) will find the Signposts program effective in managing their child's behaviour.

These Acquired Brain Injury Parent Notes are a supplement to the Signposts generic program. It is important for you to work through all of the Signposts modules, beginning with the Introduction.

Because all families are different, the relevance of each module will vary. By working through all the modules you will be able to decide which strategies work best for your child and your family, and draw up a plan of action that suits your needs.

Some families will see changes in their child's behaviour after they have implemented Module 2; others will need to work through all the modules before significant changes are seen. Even if you observe changes in your child's behaviour early on as you apply the strategies of the Signposts program, we recommend that you still complete Module 5 as it focuses on preventing further difficult behaviour developing.

Dealing with stress in your family and *Your family as a team* are particularly relevant to families of children with acquired brain injury. Research has shown that such families experience very high levels of stress, and so it is important to work through both of these modules.

About acquired brain injury

Research tells us that around 160,000 Australians have some form of brain injury. Some of the terms used to describe brain injury are:

- acquired brain injury (ABI)
- traumatic brain injury (TBI)
- head injury.

While there may be some subtle differences between the exact meanings of these terms, they all refer to injuries to the brain that occur after birth and in some way effect the functioning of the person injured. This includes damage caused by infection, disease, lack of oxygen, or a blow to the head. The Signposts supplementary materials use the term acquired brain injury, but the information applies to all forms of brain injury.

ABI is a complex and difficult thing to understand. The brain is made up of millions and millions of cells. When brain cells are damaged and die they do not grow back, however some damaged cells do recover with time. Also, different parts of the brain can sometimes take over what another part of the brain used to do, so a child with ABI may keep improving for many years.

The brain controls all functions of our body and everything we think, say and do – in other words, who we are. In children the brain is still growing, so as well as the effects of ABI, other changes occur because your child continues to develop over time.

The precise effect of any brain injury will depend on the part of the brain that is injured. The brain is a complex organ and injuries to different parts will have differing effects on the individual concerned. It is very important to consult with relevant specialists to get as accurate a picture as possible of your child's condition.

The information in this booklet might be enough for your family but if you want to know more don't be afraid to ask questions or seek out further information. See Resources for further information and contacts.

Differences between acquired brain injury and other disabilities

Here are some of the differences between ABI and other disabilities. Each of these points can affect both the behaviour of your child and the strategies needed to manage the behaviour.

- No two children with an ABI will be exactly the same. While there may be some similarities, the details of the actual injury to the brain will be different and so the overall outcome for each child will be different.
- A child may have average or above-average intelligence, but still not be able to learn new information or make use of the information already known.
- Some children with ABI are likely to remember that they could once do things they can no longer do because of their ABI.
- Some previously established skills and knowledge may be retained which can be used to assist further learning.
- A child with ABI may look the same as other children but think and act differently.
- The combined effects of injury to different parts of the brain may create different or additional problems.
- After an ABI occurs, recovery and improvement may be rapid at first and may then slow or appear to stop, but recovery and improvement can continue for many years, even throughout a lifetime.

Effects of acquired brain injury on a child

Injury to the brain can affect behaviour, and the ability to learn new ways of behaving. Here are some of the ways in which ABI can affect a child.

Cognitive

ABI often affects the area of thinking and reasoning. You might read or hear the terms such as ‘cognitive’ or ‘cognition’ in information about ABI and behaviour. ‘Cognitive abilities’ describes the way we use our brain to think and to use our skills and knowledge, just as ‘physical abilities’ describes the way we use our bodies to move around and do things.

When a person has trouble with a part of their thinking it is called ‘cognitive disability’. Cognitive outcomes that occur after brain damage include:

- trouble concentrating or paying attention
- not being able to remember or learn new things
- being disorganised and not able to make a plan
- having difficulty with reasoning and solving problems
- being slower at processing information
- seeming to be stuck on one track and not able to change
- not being motivated to start things.

Social and emotional

The development of social skills and being able to behave appropriately in social situations can be affected by ABI. For example, a child with ABI may not remember to take turns in conversation or games.

The ability to respond appropriately emotionally can also be affected by ABI. For example, a child may laugh when hearing a sad story or laugh or cry very easily. A child with ABI may find it difficult to stop laughing at a joke even after everyone else has finished laughing.

Physical and health

The brain controls everything our body does so many physical and health functions can be affected by ABI. Some physical effects include tiredness, weakness on one side of the body and poor coordination.

Examples of how health may be affected include frequent headaches, hormonal changes, epilepsy and the loss of the ability to control the bladder or bowel.

Sensory

The brain interprets the messages from our sensory organs such as our skin, eyes and ears. An injury to the brain may cause an inability to correctly read and interpret these messages. For example, a child with ABI may not be able to detect pain, may have lost the sense of smell or taste or may have vision or hearing difficulties.

Communication and language

Communication and language can be affected by ABI in a range of ways, some of which are very subtle. These include difficulty understanding written or spoken words, getting words wrong, slurred speech or rambling speech due to difficulty in planning what to say.

Behaviour

The effects of ABI on behaviour can include becoming irritable or angry more easily, behaving inappropriately (for example, touching people in an inappropriate way), acting younger than their age or rushing into things without thinking first. These kinds of changes in behaviour vary in degree and may increase when combined with tiredness or other changes.

Even with knowledge about ABI, it can still be difficult to work out:

- what behaviour is linked to the ABI
- what is a reaction to changes the child is experiencing
- what is simply a part of the child's normal development.

For example, a child who has been well behaved and friendly may quite suddenly become rude and aggressive. Is this change due to the effects of the ABI, to the fact they have become a teenager or because, say, the family has recently relocated to a new town and new school?

Family reactions

When there is a family member with an ABI, this can affect how the whole family is able to work together. Each family member, including the child with ABI, will experience a range of feelings and emotions. It's likely that each person will experience reactions and responses in different ways, at different levels and at different times. These emotions and feelings will affect the way a family works together.

Here are some common responses of family members.

Grief

The grief and sadness parents feel after their child acquires an ABI can be like the feelings experienced after the death of someone close. While we have socially acceptable ways to mourn and grieve when a person dies, such as providing support, food, comfort and understanding, we do not have the same ways to mourn and grieve when a person has had a significant event such as an ABI. It may feel very uncomfortable to mourn when the person is alive, even though they have changed significantly.

Friends and extended family can find it difficult to understand what is happening, particularly as there are often no visible signs of injury. The child may begin to realise what has been lost and may then have periods of sadness and grief.

Each transition and adjustment may bring new feelings of grief and loss – for example, comparing what is happening now, with what was possible before the ABI. It can also be very painful seeing a child's friends and siblings going through life changes, such as moving on to high school or getting a job, when these milestones are now much more difficult for the child.

While it is important to acknowledge your grief, it is equally important for families to look for new and positive ways to view life's changes.

Guilt

Individual family members may feel guilty because they believe they should have done (or not done) something that could have prevented the ABI (for example, 'If only I had called the doctor sooner' or 'If only I had picked him up from school instead of making him walk home').

Guilt can also occur because of something the parent is now doing or not doing (for example, parents may feel that they have managed a situation badly or get tired and irritable and say something they later regret).

Blame

Like guilt, blame can occur when a family member believes the ABI was preventable (for example, 'If only Dad had made sure Joe's seatbelt was done up before they left'). Blame can lead to anger and resentment within a family. Sometimes family members may believe the person with ABI could have prevented it themselves (for example, saying, 'She shouldn't have crossed the road' or blaming a child for abusing drugs or alcohol or taking an overdose).

Fear

Fear can affect the way families work together and how they manage difficult behaviours. For example, a family member may be afraid of the consequences of taking risks. Common fears include:

- fear of the event that led to the ABI
- fear that an accident will happen again
- fear that an accident can happen to anyone
- fear about what will happen if the family, or person providing the care, is no longer able to do so
- fear about the child's future
- fear about letting the child or other family members down.

Anger, frustration and resentment

Following a significant event such as an ABI so much of family life is suddenly out of control and there are huge personal and family adjustments to be made. Feelings of anger, frustration and resentment may be the result of:

- the event that led to the ABI
- giving up work to provide care
- believing that others are not doing enough
- feeling that everything is happening so slowly
- the way other people respond
- uncertainty about the future.

Frustration and resentment may be unspoken or it may show in bursts of shouting or abuse. These feelings will influence how effectively difficult behaviours can be managed and how well the family can work together as a team.

Hope

The feelings and reactions families experience are not always negative. Throughout the stages of recovery and life, hope can be important for family members. Other positive feelings that families of children with ABI report are relief and joy that the child is still alive or not more seriously injured, and feelings of joy for positive changes in their child or in themselves.

Family adjustment

There are all kinds of adjustments to be made after your child has an ABI. These adjustments will be different for each family and for each person within the family.

Common adjustments include:

- a feeling that you have a new or different child – your child may look just the same but may behave very differently
- changes in family roles (for example, a parent might leave their job to care for a child with ABI; a brother or sister may need to take more responsibility for running the household; a mother may have less time for siblings)
- changes in your role as a parent (for example, a teenage child who was becoming much more independent now suddenly needs more care and supervision)
- changes in daily routine (for example, a routine such as getting up in the morning might change from free and easy to much more regimented)
- facing transitions as rehabilitation progresses and your child returns to family and community life (for example, when a child comes home from hospital, finishes treatment or starts school)
- childhood development may be delayed or may be different from your expectations
- financial changes (such as loss of work, reduced income, increased cost of support and equipment)
- changes to family life (for example, not being able to go out as easily, more people coming and going in the house or having to choose outings carefully to prevent incidents)

Family challenges

Physical, cognitive and personality changes following ABI can affect the whole family. The child may seem a different person. It is important to remember that the child may not be able to control certain behaviours; they are not deliberate.

‘Whatever I do, it’s never enough’

Although family members are doing all that they can, some may experience feelings that they are not doing enough or that others are not doing enough. This can lead to feelings of frustration and resentment and breakdown of the family spirit.

Lack of understanding from others

Often people outside the family – including extended family, friends and people in the community – don’t understand what a family member is going through. They don’t understand ABI and its impact on the whole family.

They may not understand how much energy and effort is required to support your child. They may tell you what to do, make hurtful comments and even criticise. This can be very difficult to deal with.

Changes for brothers and sisters

When a child in the family has ABI, brothers and sisters can face many challenges from the time of the injury, throughout the process of recovery, and beyond. Here are some examples:

- They may have been present at the time of injury or illness and imagine themselves as responsible.
- Routine and lifestyle change significantly while parents look after the injured sibling at hospital and then at home.
- They may be doing more around the house, providing care for their brother or sister and taking over some of the parenting role.
- They may have feelings similar to parents, such as sadness, frustration, anger, fear, guilt, resentment.
- They may be embarrassed by their sibling’s behaviour and may not want to go out with them or invite friends home.

It is common for siblings to keep their feelings hidden to avoid upsetting their parents. Silence does not always mean things are okay.

Like their brother or sister with ABI, siblings often also show great strength, understanding and resilience in their new situation. Acknowledge this whenever you can.

Supporting brothers and sisters

How well brothers and sisters cope can affect a family's ability to function as a team and may contribute to difficult behaviour in the child with ABI. Here are some ideas on how to develop coping strategies and give reassurance:

- Give your time, listen and encourage each child in the family to express their thoughts and feelings.
- Acknowledge the strengths of brothers and sisters.
- Let them know that other siblings in similar situations share their experiences.
- Support brothers and sisters to be part of the family team, working together as a family.
- Give them a break from their sibling with ABI. Where possible, try to make time for them to be alone with one or both parents.
- Share information about ABI to help them understand what is happening and encourage them to contribute.
- Try not to overload them with information or give information that is beyond their understanding.
- Answer questions when they come up with simple explanations and add further information when needed.
- Let their teachers know what has happened to their sibling and the impact this is having at home. It may be possible to adjust homework expectations or deadlines, and to get support from the school counsellor or welfare officer.
- Encourage outside help from family, friends or professionals when needed.

There are some excellent internet sites for the siblings of children with a disability (see Resources).

Role of medication for your child

As indicated earlier, ABI is a complex phenomenon and the exact impact of the injury will depend on the parts of the brain that have been damaged. The most effective treatment for your child might include regular medication, and it is important that you consult specialists in brain injury for advice about this.

If medication does play a role in the treatment of your child's ABI, you will still find Signposts strategies for behaviour management useful in conjunction with any medication used to address factors which influence behaviour.



Parent Notes

Module 1

Acquired Brain Injury: Measuring your child's behaviour

Module 1 Measuring your child's behaviour

To be successful in helping your child with an ABI learn better behaviours, one of the first steps is to describe your child's existing skills. Module 1 helps you to accurately measure your child's behaviour using a behaviour graph. From this foundation you can measure improvement. You also begin an action plan.



Module 2

Acquired Brain Injury: Systematic use of daily interactions

Module 2 Systematic use of daily interactions

One key component of Module 2 is learning about the effects that consequences have on behaviour. Module 2 also shows how you can use consequences to teach new behaviours.

A concern that is sometimes expressed about children with ABI is that their memory problems may prevent them learning from consequences. It's important to keep in mind that for children with ABI the injury to parts of the brain is quite different from one individual to another, so some children may have major impairment to memory and others may have none. So even if a child's memory is affected, teaching consequences can still be effective.

A major review of research into interventions for children and adults with behaviour problems after brain injury found that interventions based on the systematic use of consequences were very effective. The critical features are the timing and the nature of consequences.

Timing of consequences

If your child's memory has been affected, it is essential that you provide consequences (positive or negative) immediately after the behaviour. If you delay consequences, a memory problem will increase the likelihood of your child not connecting the behaviour and the consequence.

Nature of consequences

It is important to note that the actual consequences are important to the child. While this is relevant for both positive and negative consequences, it is particularly important for positive consequences. It may be that your child has very different likes and dislikes now compared with before the injury.

Another important component of Module 2 is how you deal with household rules. If your child's memory is poor, it is important to have as many visual representations of your household rules as possible. You could pin up drawings of tasks to be completed in prominent places, like the refrigerator or on your child's bedroom door.



Parent Notes

Module 3

Acquired Brain Injury: Replacing difficult behaviour with useful behaviour

Module 3 Replacing difficult behaviour with useful behaviour

Module 3 helps you to understand some of the reasons why your child displays difficult behaviour and focuses on ways of replacing difficult behaviour with useful behaviour.

Children's difficult behaviour always has a purpose. It might be to get attention, or to get out of having to do something, or be related to a number of other reasons. This module begins to help you identify the purpose of your child's difficult behaviour and develop strategies to replace that difficult behaviour with more appropriate behaviour.



Parent Notes

Module 4

Acquired Brain Injury: Planning for better behaviour

Module 4 Planning for better behaviour

One key component of Module 4 is the establishment of daily household routines. If your child has problems with memory, this could limit the effectiveness of any routines so, again, visual representations such as drawings and charts could be helpful in getting your child to follow routines.

Another component of Module 4 is the use of a planned activities routine for high-risk situations. These routines typically involve preparing activities for your child to engage in while you are occupied in another important family activity. Given that some children with ABI are not able to concentrate on tasks for very long, it is important to provide a range of activities for your planned activities routine.



Parent Notes

Module 5

Acquired Brain Injury: Developing more skills in your child

Module 5 Developing more skills in your child

One of the key messages in Module 5 is that teaching your child new skills is a good way to prevent new difficult behaviours developing. This means that you will help your child build on existing skills. Children with ABI may well have lost some skills as a result of sustaining the injury, but they will retain very many skills that you can build on. You will need to observe your child carefully to see what skills, if any, have been lost.

One concern that is often expressed about children with ABI is that they become very frustrated if they make mistakes while trying to achieve something new. If you feel that this is happening with your child, you can try using a promising new procedure used with children with an ABI called 'errorless learning'. This involves designing learning tasks that your child will be able to achieve, with you providing lots of help. It's like taking small steps at a time. When this teaching method is used effectively, the child learns what is needed but does so without failing and becoming frustrated.

If your child's injury has damaged a part of the brain that is used for planning future tasks and activities you might be interested in a new technique for teaching new skills called 'executive function training'. Considerable research is going into this technique, which is basically teaching the child a general skill of planning for an activity. The steps include the following: decide upon a goal, develop a plan to achieve that goal, carry out the plan, and then review how things went. While this procedure is still experimental, you might consider using it when selecting new skills to teach your child with ABI.



Parent Notes

Your family as a team

Acquired Brain Injury

Your family as a team

This module helps you think about how to work as a team and support one another as you make changes in the ways you are managing your child's difficult behaviour. Use the generic Signposts program module to help you think about these issues.



Parent Notes

Dealing with stress in the family

Acquired Brain Injury

Dealing with stress in your family

This module helps you identify what stresses you and ways to manage stress so that you are able to make best use of the program. Use the generic Signposts program module to help you deal with these issues.

Parent Notes

Resources

Acquired Brain Injury



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Websites and further reading

In addition to the resources listed in the Signposts Introduction module (page 12), here are some resources specific to acquired brain injury.

Organisations

The Bouverie Centre provides statewide specialist services to families and professionals dealing with ABI, such as counselling for families, consultation and training services for professionals and research on family adjustment to ABI.

The Bouverie Centre
ABI Specialist Team
50 Flemington Street
Flemington Vic 3031

P: (03) 9376 9844
E: bouverie.centre@latrobe.edu.au

The Melbourne City Mission Statewide ABI Paediatric Coordinators provide services for people working with children and young people with ABI in Victoria. Services include providing information and education about children and young people with acquired brain injury, and behaviour-management education and training.

Melbourne City Mission
Statewide ABI Paediatric Coordinators
219 Brunswick Road
Brunswick Vic 3056

P: (03) 9385 6333

Southwest Brain Injury Rehabilitation provides acquired brain injury rehabilitation services to adults and children in the southwest region of New South Wales.

P: (02) 6041 9902
F: (02) 6041 9928

BrainLink is a statewide service that provides information and support to those affected by acquired brain injury and their families.

BrainLink
The Nerve Centre
54 Railway Road
Blackburn Vic 3130
Freecall: 1800 677 579
P: (03) 9845 2950
W: www.brainlink.org.au

The Disability Intake and Response Service is part of the Victorian Government Department of Human Services. It provides information about disability funding programs for children and case-management and funding packages for children and young people.

Freecall: 1800 783 783

Paediatric Rehabilitation Service, Royal Children's Hospital, is designed to improve the abilities of children and young people following major injury or illness which affect their function. Programs help the child participate in activities at home, school and the community and are linked in with community-based services.

Paediatric Rehabilitation Service
3rd Floor, SE building, Royal Children's Hospital
Flemington Road
Parkville Vic 3052

P: (03) 9345 5283
E: rehab.service@rch.org.au
W: www.rch.org.au/rehab

Websites and further reading

Association for Children with a Disability: an information, support and advocacy organisation for children with a disability and their families in Victoria, Australia.

Association for Children with a Disability
Suite 2, 98 Morang Road
Hawthorn VIC 3122
590 Orrong Road
Armadale Vic 3143

Freecall 1800 654 013 (for rural callers)
P: (03) 9818 2000
W: www.acd.org.au

Kids Health Info: The Royal Children's Hospital website with fact sheets on a range of medical topics including acquired brain injury in children. Download free of charge.

W: <http://www.rch.org.au/kidsinfo/factsheets.cfm>

Paediatric ABI Fact Packs: fact sheets for parents of children with ABI produced by Southwest Brain Injury Rehabilitation Service.

P: (02) 6041 9902
F: (02) 6041 9928

Parents Guide: Growing Up with ABI: a comprehensive resource book for parents with a child with acquired brain injury.

Brain Link, The Nerve Centre
54 Railway Road
Blackburn Vic 3130

Freecall: 1800 677 579
P: (03) 9845 2950
E: admin@brainlink.org.au
W: www.brainlink.org.au

Step by Step: A guide for families with children and adolescents with an acquired brain injury: a series of five booklets produced by the Sydney and Westmead children's hospitals and the Motor Accidents Authority.

Booklet 1: An Introduction to the Brain Injury Rehabilitation Team

Booklet 2: Understanding the Causes and Effects of Brain Injury

Booklet 3: Physical Recovery and Learning after a Brain Injury

Booklet 4: Family, Emotions and Going Home

Booklet 5: Medico-legal Advice, Teenagers and Contact Numbers

Download free of charge from Westmead website > Professionals > Services > Rehabilitation > Brain Injury Service > Resources

W: www.chw.edu.au

Your Shout: a website for adolescents who have a brother or a sister with a disability or illness. Created by a group of teenage siblings and the Association for Children with a Disability, Your Shout encourages siblings to contribute their stories, thoughts and opinions in a variety of different formats.

W: www.yourshout.org.au