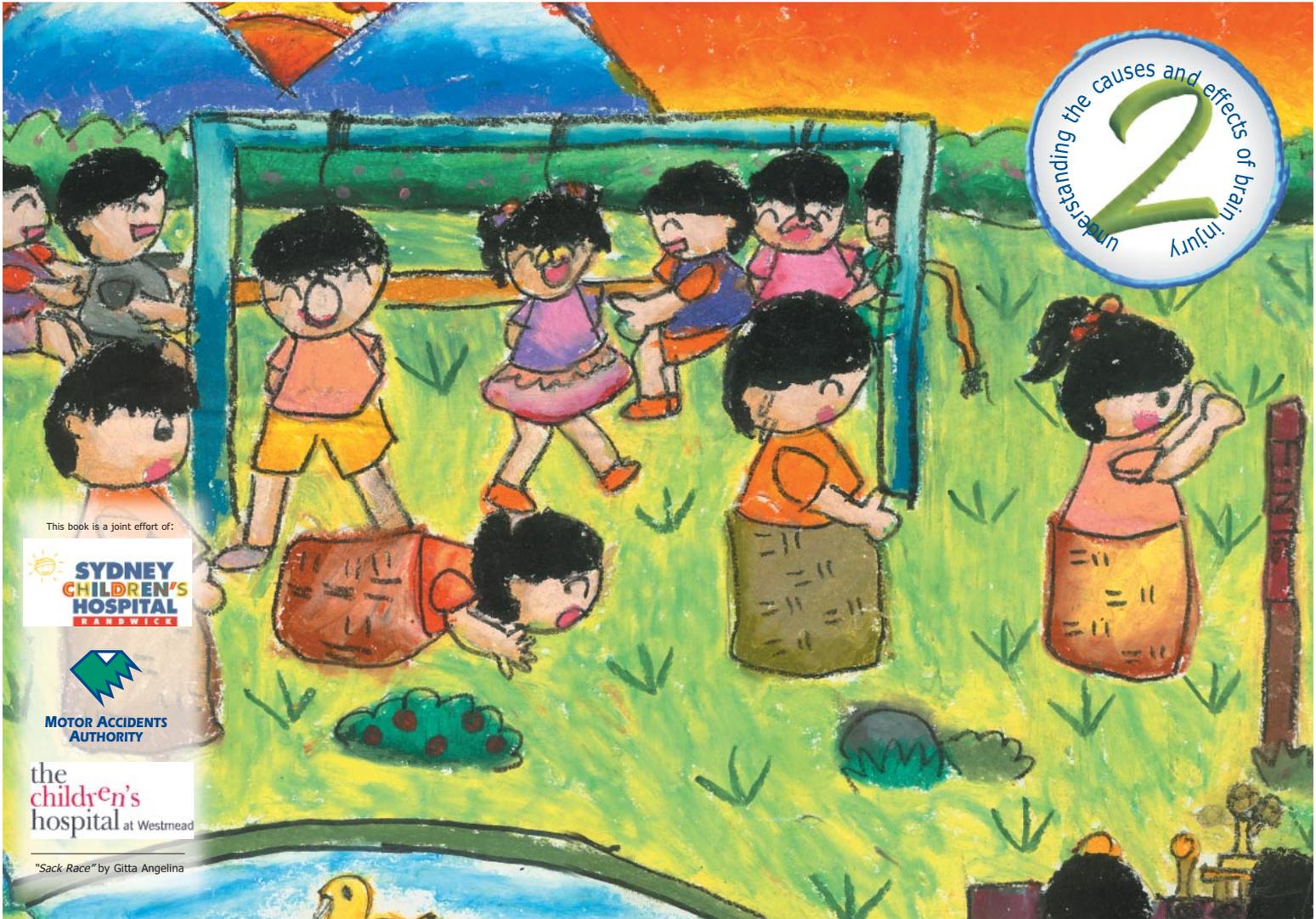


Understanding the causes and effects of brain injury

# 2



This book is a joint effort of:



MOTOR ACCIDENTS  
AUTHORITY

the  
children's  
hospital at Westmead

"Sack Race" by Gitta Angelina

# STEP BY STEP:

A guide for  
families of  
children and  
adolescents with  
a brain injury

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This project was made possible through help and encouragement given by many people, including staff of the Brain Injury Rehabilitation teams at Sydney Children's Hospital, Randwick and The Children's Hospital at Westmead. Parents and carers of children with brain injury were involved from the earliest stages and contributed during the development process. Children from local schools and hospitals have illustrated the booklets and families have provided personal stories.

Information in these booklets is based on the team's experience, literature published by other organisations, and conversations with families and children with brain injury. It is intended as a guide, and families should seek professional advice as needed. Please note that some of the information provided may become outdated over time.

The information for these booklets was edited by Dr Adam Scheinberg (Paediatric Rehabilitation Specialist), Donna Carmichael (Co-ordinator at the Sydney Children's Hospital, Randwick), and Lynn McCartney (Clinical Nurse Consultant at The Children's Hospital at Westmead). The booklets were funded by a grant from the Motor Accidents Authority.



**MOTOR ACCIDENTS  
AUTHORITY**

the  
children's  
hospital at Westmead

Brain Injury Rehabilitation Program  
Sydney Children's Hospital, Randwick  
Phone: (02) 9382 1590

The Brain Injury Rehabilitation Service  
The Children's Hospital at Westmead  
Phone: (02) 9845 2132

# THE EARLY STAGES OF BRAIN INJURY



Following an injury or illness, your child would have been admitted to the Emergency Department. Many tests may have been done to help determine what treatment was required. It may also have been necessary for your child to go to the Paediatric Intensive Care Unit (PICU).

In this section, we describe some of the procedures and tests that happen in the PICU, who is involved and how children recover during this time. Parents often ask, "how long will it be" before their child has recovered. In the early stages, we often can't give accurate information about this, as there are many different factors which influence recovery. In nearly all cases however, children with a brain injury improve with time.

## What are the common treatments seen in the Intensive Care Unit?

During this time your child may be unconscious and sedated. They may be attached to specialised equipment that monitors heart rate, blood pressure and temperature.

Other treatments you may see include:

- **Ventilation** – if your child is not able to breathe safely, it will be necessary for a machine to breathe for them. When your child is alert

enough to breathe, the ventilation and sedation will slowly be reduced and the breathing tube removed. In certain situations, it may be necessary to perform a tracheostomy to help a child breathe without the ventilator. At a later stage, the tube is removed and the child is able to breathe normally again.

- **Cerebral pressure monitoring and intra-ventricular drain** – in the acute phase following brain injury, the brain can become swollen. To relieve pressure on the brain, the neurosurgeon will decide if a pressure monitor and/or ventricular drain is required. The tube would normally be removed prior to discharge from the intensive care to the ward.
- **Intravenous fluids** – some children will be unable to eat or drink normally and may require a drip (IV cannula) into their vein to deliver fluids and medications. This is connected to a pump to make sure the fluids are given at the correct rate.
- **Naso/orogastric tube (NG tube)** - this tube goes from your child's nose or mouth into the stomach. Initially it is used to keep their stomach empty and prevent vomiting. Later it can be used to give nutrition. Your child can still eat and drink with the nasogastric tube in place and when they are

eating enough, the tube is simply removed.

- **Urinary catheter** – initially a catheter into the bladder may be needed to help measure your child's urine volumes.

## Who looks after your child in the PICU?

A number of health professionals will be involved in the care of your child in the intensive care and it may be useful for you to know what their roles are, so that they can answer your questions. You have the right to information, as soon as possible and repeated as often as you need in order to understand what is happening to your child.

- **Intensive Care Doctors:** are responsible for your child's day-to-day care while they are in PICU. They monitor your child's breathing, nutrition, fluids and medications as well as their overall recovery.
- **Neurosurgeon:** this is a specialist surgeon trained to care for a variety of brain and spine problems that may require surgery. The neurosurgical registrar is the assistant to the neurosurgeon. You may find that your initial contact is with the registrar, so ask them to explain what is happening when you feel that you need to.

- **Nurses:** are available to talk to should you have any questions about the nursing care your child is receiving. The nurse caring for your child each shift is the best person to speak with to explain how your child is doing and what procedures may be taking place.

- **Other doctors:** if your child has other injuries such as abdominal trauma, a general surgeon will be involved. An orthopaedic surgeon would be involved if your child has any broken bones.

## What tests may be performed in the early stages?

When your child is in hospital, some of the specialised tests that may be carried out include:

- **Computerised Axial Tomography (CAT Scan)** This is a specialised X-ray that gives better images of the brain than normal X-ray and helps doctors to work out if there is bleeding, or swelling of the brain.
- **Magnetic Resonance Imaging (M.R.I)** This scan of the brain can give views of areas that cannot be seen on other scans. It is not normally used unless more information, than is provided by the CAT scan, is needed.

- **Electroencephalogram (E.E.G)**  
An EEG shows the electrical activity in the brain. Small external recorders are placed on the head and these make tracings of the brain's activities. It can give information about whether fits (seizures) are occurring or not.

Although these tests are very important for trying to find how severe a child's brain injury is, they are only a guide, and can't give specific information about whether there will be long-term problems.

### How long will your child need to stay in the PICU?

The intensive care specialist, with the other specialists involved, will decide when it is safe for your child to be transferred to the ward. This is usually after they no longer require ventilation, and are medically stable. It is often at this time that the Rehabilitation team will become more involved in the care of your child.

## PARENTS' TIPS

- You can ask to go with your child when they have tests such as a CAT scan. Ask nursing staff about this.
- Family and friends can visit in the PICU but visitors need to be limited to 2 at a time. Immediate family can visit at any time, however there are set visiting times for friends during the day.
- Bring familiar things in from home for your child, rather than buying "new" toys. Your child is more likely to be comforted by familiar things.
- Don't talk about your child "over the bed". Even though they may seem to be asleep or sedated, they may in fact be able to hear and understand part of the conversation.
- Even though your child may not respond at this stage, continue to talk to and comfort them.
- Ask the social worker about accommodation options, meal tickets, and transport.

## THE EFFECTS OF BRAIN INJURY

In this section, we describe the causes, classification, and effects of brain injury. We also describe how we measure the severity of an injury.

### The most common causes of brain injury in Australia are:

- Motor vehicle and bike accidents
- Falls
- Sporting injuries
- Meningitis/encephalitis (infections around the brain)
- Cerebrovascular accidents (stroke)
- Hypoxia (lack of oxygen to the brain) from near-drowning accidents, cardiac (heart) causes and prolonged fits

Most of the information in this booklet relates to children who have had a brain injury following trauma. There may be similarities with children who have had a brain injury from another cause such as stroke or infection. Discuss the differences for your child with the team.

### What are the different classifications of brain injury?

Brain injury can be classified as *focal* or *diffuse*.

- *Focal injury* usually occurs following a direct blow to the head, causing a skull fracture. There is often bruising to the brain underlying the fracture.

*Diffuse injury* is often a result of motor vehicle accidents or falls where there has been shaking of the brain. This results in damage to the connections between nerve cells, termed *diffuse axonal injury*. The damage is more widespread than in focal injury, and therefore there may be more problems.

### What are some of the effects of brain injury?

There may be changes affecting physical function, cognition (thinking) and communication.

The short-term effects include *coma* (being unconscious) or *concussion*, (being confused and drowsy). The period of time your child stays in a coma is related to the severity of the initial injury. In the longer term, physical problems include weakness, poor balance or co-ordination, and fatigue. Cognitive effects can include reduced attention and concentration, difficulty with planning and organisation, changes to behaviour, and changes in communication such as expression and understanding what is said. All these areas are discussed in later booklets. It is important to note that most problems improve with time and the Rehabilitation team will be working with you and your child to maximise their recovery.

### How do we measure the severity of traumatic brain injury?

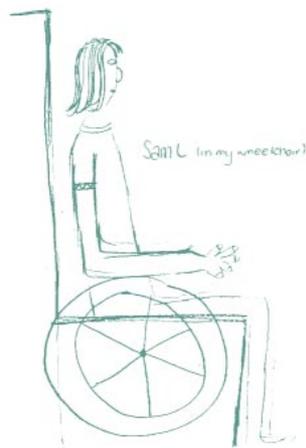
Parents often want to know what the future holds for their child after injury. It takes time to tell how serious your child's injury is, and what long term effects there may be.



By DAVID AGE 10

The most reliable way to assess the severity of the initial injury is to measure the amount of time your child remains confused, disoriented and has poor day-to-day memory. This state is termed *post-traumatic amnesia* and is discussed in more detail later in this booklet.

Other factors that the team can use to judge severity of injury include the *Glasgow Coma Scale Score (GCS)*, and length of coma. The GCS score is used to assess the level of coma by checking how well your child can respond to commands. Coma is when the brain is not functioning at its normal level, as the part of the brain responsible for keeping us aware of what goes on around us, is affected. During this time your child may have difficulty communicating or responding to light, sound and touch.



*Brett was 10 months old when he had his accident, which left him with a severe brain injury. We were told early on that he might not live. Yet after 8 weeks in hospital we were going home, but with a different boy. He could not do anything and just lay there. He could barely move his arms and legs. He couldn't hold up his head and no one thought he would change very much.*

*Then 2 weeks after we went home, he rolled over. About 5 weeks later he started to commando crawl. We were lost for words. Then after 2 months, he sat up. We were so happy that he could do these things, and knowing that he will more than likely walk in the future.*

*So when there are times that you think things won't get any better, always have hope because things are better around the corner.*

## HOW THE BRAIN WORKS



The brain is part of the central nervous system, which includes the brain, the brain stem, the cerebellum and the spinal cord. The brain is made up of nerves, which are cells that send and receive electrical impulses, to and from the body.

The brain is divided into halves, called hemispheres. There is a right and left hemisphere and each hemisphere controls the opposite side of the body's movement.

The hemispheres are further divided into lobes, which are parts of the brain that serve specific purposes. These include the frontal lobes, parietal lobes, temporal lobes, and occipital lobes. In focal brain injury, just one lobe in one hemisphere may be affected. In diffuse injury, several or all lobes of both hemispheres may be affected.

### What are the effects of injury to the different lobes?

*Frontal lobes* – the frontal lobes control most complex functions, which are referred to as “executive functions”. These include planning, control of impulses, initiation, attention and emotion. The back of the frontal lobe also controls movement of the opposite side of the body.

Damage to the frontal lobes may cause changes in behaviour. This can

be one of the most upsetting aspects of brain injury for parents. Ways of managing these changes are discussed in later booklets.

*Parietal lobes* – the parietal lobes provide sensory information about the body such as touch, pain and temperature. Injury can result in abnormal sensations. Children with weakness on one side of their body may have a lack of awareness of that side.

Damage to the parietal lobes can also affect spatial orientation, which is how children orientate themselves in space. This may result in difficulties with producing pictures and models.

*Temporal lobes* – the functions of the temporal lobes include hearing, memory and learning. Damage may cause difficulties with organising what to say and using the correct word. It may also result in loss of short-term memory. This may have an effect in situations such as school, where memory is important in learning new information.

*Occipital lobes* – the occipital lobes help us understand what we see. They interpret the color, shape and distance of the object the person is looking at.

Damage to the occipital lobes may result in a distortion of what the person can see. Some children may have difficulty recognising or interpreting familiar objects.

### 5 ■ How long will my child take to get better?

Getting better after brain injury happens at a different rate for every child but usually continues for a long period of time. Recovery is often most rapid in the early stages.

Whereas an adult has reached a level of maturity where they know how to perform the tasks needed for daily life and work, for many children, these tasks are yet to be learnt. Brain injury can affect the ability to learn these new skills. The Rehabilitation team will help you and your child to relearn skills which have been lost, and to accomplish skills which need to be learnt over time.

*The Brain stem* – the brain stem connects the brain to the spinal cord and sits beneath the brain. Nerves to the face, including those to the muscles for swallowing, arise here and if damaged, may interfere with sensation to the face and mouth, swallowing and coughing.

*The Cerebellum* – the cerebellum controls the co-ordination of movement for the body. It is found towards the back of the brain.

Damage to the cerebellum may result in a lack of coordination such as being wobbly when walking, clumsy when using hands or slurred speech.

## PARENTS' TIPS

- Ask your doctor to show you your child's brain scans, or to demonstrate on a plastic model, the different parts of the brain.

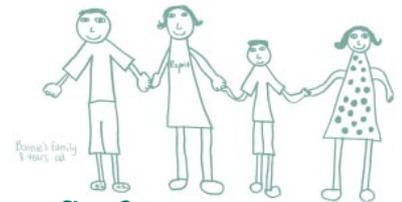
## STAGES OF RECOVERY

The length of time it takes for your child to improve will differ in each case. How long this recovery will take, is probably the hardest question for the doctors to answer, especially in the early stages. Recovery is usually most rapid in the early weeks and months. An unconscious child rarely wakes up all at once, as may be suggested on TV or movies. Rather, children usually recover gradually.

Below is a stepwise description of the way children often recover from significant brain injuries. It is based on a scale called the Rancho Los Amigos scale, named after the place where it was devised. When children recover from brain injury, they may go through some or all of the stages.

### Stage 1: NO RESPONSE (Earliest stage)

- The child appears to be in a deep sleep and doesn't respond to sounds or stimulation. This may be referred to as "coma".
- In a coma, the brain is not functioning at its normal level. During this time there is a limited ability to take in information or respond to light, sound and touch.



### Stage 2: GENERALISED RESPONSE

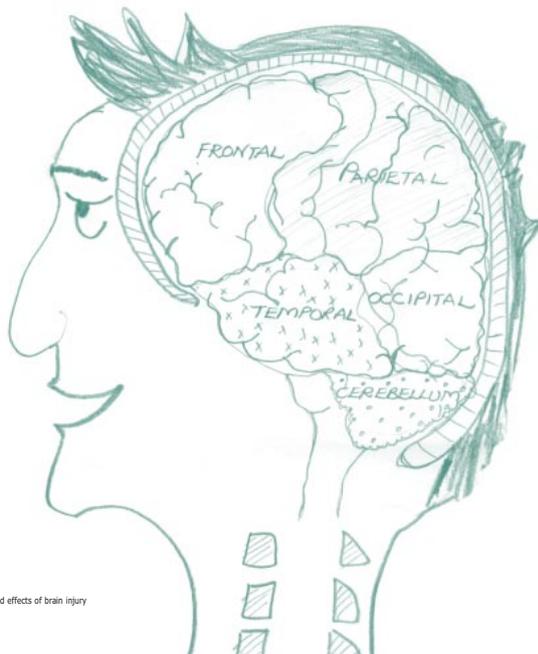
- As the child's injured brain recovers, they will begin to react to loud noises or painful sensations by making noise or moving arms and legs.
- This response may not happen frequently and they may still appear to be asleep for much of the time.

### Stage 3: LOCALISED RESPONSE

- The child may respond by moving away from uncomfortable procedures such as needles.
- They may also turn towards sound or try to watch people in the room.
- They may respond to a simple instruction such as "close your eyes".

### Stage 4: CONFUSED – AGITATED

- Children's behaviour is variable during this stage. They may be inactive or restless, loud or even agitated. They are not in control of this behaviour.
- They may be confused and try to wander. However they may not know where they are going and need more supervision.
- The child's attention span is short, and they may forget things that have happened to them.





- Although they are more aware of what is going on, they can't make sense of it all. While this behaviour is distressing for parents, it does show that the child's condition is improving.

- They will start to show that they remember simple day-to-day things such as the names of staff.
- They may be able to work at tasks in therapy sessions for longer periods.

#### Stage 5: CONFUSED – INAPPROPRIATE

- Children are usually calmer at this stage and able to do simple tasks for themselves, such as finger feeding.
- They may become agitated if they are over stimulated, or asked to do something they are unable to do.
- They will start to talk more clearly, but what they say may seem inappropriate.

#### Stage 6: CONFUSED – APPROPRIATE

- Children may still be confused during this stage but start to behave more appropriately.

#### Stage 7: AUTOMATIC – APPROPRIATE

- The child is able to do normal activities with only a little help.
- They may be able to learn things but it may be slower and harder than before.
- The child tires quickly.

#### Stage 8: PURPOSEFUL – APPROPRIATE

- The child is able to recall past information and recent events, and better understand what happened to them. They may be upset about what has happened.
- The child may have changes in their thinking, concentration, memory and social skills compared to before the accident.

## WHAT IS POST-TRAUMATIC AMNESIA (PTA)?

When a child is 'waking up' after coma, the steps of recovery are often combined and referred to as post-traumatic amnesia (PTA). This is when they are unable to remember day-to-day events that have occurred, such as who came to visit them. They usually can remember up to the time of injury, but have problems remembering what happened afterwards. Children in PTA are often confused and disorientated, which means they may not know where they are, or what time of day it is.

It is important that while your child is in PTA, they are in an environment where they don't become over stimulated. They may not be able to cope with too much noise, or activity. It may be necessary to limit the number of people who come in to visit to one or two at a time. If they are at risk of climbing out of bed and hurting themselves, it may also be necessary to put their mattress on the floor.

The positive aspect of PTA is that the child will usually not remember much of what has happened to them during this time. Little pockets of memory may surface, but most of this time will not be remembered.



It is important to know that the length of PTA can be hours, days, weeks or months. We use the length of PTA to help predict if a child will have long term changes after their injury. Most children come out of PTA, even in the most severe cases. It is not until your child is out of PTA that further assessments can be done to see what specific changes may have occurred.

## PARENTS' TIPS

- Children may recover in a stepwise fashion like in the Los Ranchos scale. However they may skip levels, have signs from more than one level at a time, or stop at a level in their recovery.
- You will be able to get information about ways to look after your child at each level from the team.

