

physical recovery and learning after an injury

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This book is a joint effort of:



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"Turtle" by Emma Scarf



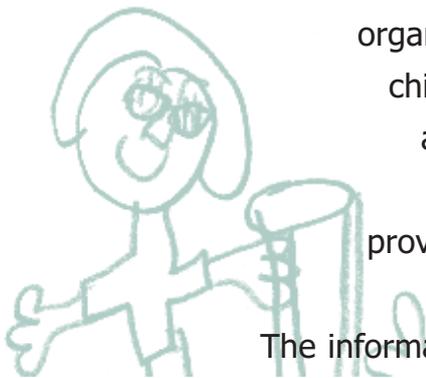
STEP BY STEP:

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

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 Please note that some of the information provided may become outdated over time.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.



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MEDICAL ISSUES



There may be medical issues that arise following your child's injury. Often different medical teams will be involved, depending on the problem. This may include the Rehabilitation team, as well as the neurology, neurosurgery, orthopedic, surgical, endocrine, and ophthalmology teams. Some of the areas we may assess further include:

- Seizures
- Raised blood pressure
- Vision
- Hearing
- Skin
- Hormones and weight
- Toileting

It is important to note that most children make a good physical recovery. They may have none, or only one of the above problems at any time. The Rehabilitation team will be able to help your child with these changes as they arise.

Do children get epilepsy (also known as fits or seizures)?

Epilepsy may occur anytime following more severe brain injuries, though tend to occur more in the first few weeks following the injury. This may include staring episodes, or twitching of arms or legs.

Epilepsy affects about 1% of the general population. After a brain

injury, this risk increases to about 5%. The risk may be higher if there has been a focal brain injury.

Anti-epileptic medication may be commenced when your child is in the intensive care to prevent fits occurring. This will then be ceased over the following few weeks or months, provided your child has had no fits. For children who do have a fit, longer-term anti-epileptic medication may be used. Your doctor will monitor the dosage and adjust the medication accordingly.

If you observe a fit:

- Try to keep calm.
- Remove anything that could cause injury.
- Don't try to restrain the child or put anything in their mouth.
- Roll the child into the recovery position (lying on their side).
- Offer reassurance and comfort.
- Ask for medical help (ask another person to do this while you stay with the child).

What is dysautonomia?

During your child's recovery they may experience periods of high blood pressure and pulse rate, sweating and changes in their breathing. This is called dysautonomia and is usually managed with medications. It is important not to overstimulate your child when this occurs.

Can eyesight and hearing be affected?

As part of the medical assessment a review by an ophthalmologist may be arranged. They will check your child's vision for such things as:

- Normal eye movements
- Ability to focus on objects clearly
- Opening or closing the eyes
- Visual fields

Your child may also need to have their hearing checked. Sometimes unsteadiness, dizziness and ringing in the ears can be related to hearing problems.

If you note any changes in your child's vision or hearing, please discuss this with your doctor.

How can the skin be affected?

When children are in bed and not moving as much, we need to take good care of their skin, particularly on the back of their head and heels. Measures will be taken, like using special mattresses and frequent position changes when possible. Despite this, a pressure sore can occur and may need dressings to heal. The risk of pressure sores reduces once a child becomes more active.



Why is my child incontinent now?

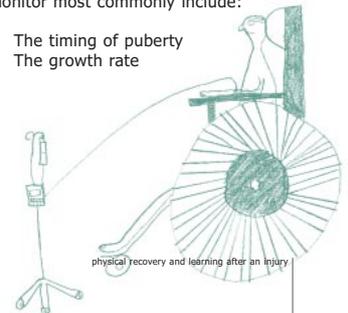
Some children, who were toilet trained, will become incontinent after brain injury because the usual mechanisms for controlling the bladder and bowel in the brain may be impaired.

In the early stages of recovery, children may require a catheter to monitor how much urine they make. As children become more aware of their surroundings, regular toileting can be restarted. During this time, some simple measures which may help, are making sure the child goes to the toilet at regular times during the day and reducing fluid intake in the evening. Using a reward chart each time the child stays dry may also be helpful. Discuss different methods of achieving continence with your doctor or nurse.

Hormonal changes:

Hormones are chemical messengers that the body uses to help regulate growth and sexual development. Following brain injury, there may be changes to the way these hormones are produced, which may have effects on development. The areas we monitor most commonly include:

- The timing of puberty
- The growth rate



If you are worried about any changes in these areas, discuss with your doctor about starting the appropriate treatment.

Weight changes:

For a few children, changes to their weight can become a problem.

There are several reasons for weight gain following brain injury, including reduced ability to do activities because of physical problems, or overeating because of cognitive changes. For instance, children whose short-term memory is impaired may forget they have just eaten, and take more food. They may also have difficulty controlling behaviour, leading to repetitive actions, including eating. Meet with the dietician in hospital to find out which foods are best for your child.

LEARNING AFTER BRAIN INJURY

In this section, we talk about the possible effects of brain injury on your child's thinking and learning, and some of the ways we can help. Changes vary with every child but usually improve with time.

Energy levels

- Your child may tire more easily, and need more rest than they used to.
- Concentrating hard may tire your child as much as physical activities.
- When children are fatigued, their behaviour might become disruptive and difficult. You may need to limit the amount of time spent on one activity or change activities regularly to avoid this.
- A common symptom of fatigue is headache, so encourage regular rest breaks if this is occurring.
- Fatigue is likely to improve noticeably in the early stages, but may persist. Activities still need to be managed carefully to avoid over tiring your child. Part-time return to school may be needed.

Concentration and Attention

- Your child's attention span may be shorter. Give them breaks during activities.
- Your child might find it hard to stay focussed on one thing and be



easily distracted. Especially in a busy environment, poor attention and concentration can make it hard for your child to follow conversations and instructions, or to take in information. Minimise distractions if possible, when your child is trying to concentrate or work.

Speed of Information Processing

- It may take your child longer to deal with, and absorb information.
- If something is said too quickly, or if there is a lot of information to remember, they may miss parts of it.
- You can help by giving information in smaller chunks and repeating instructions. Sometimes giving written information to reinforce what was said can help.

Memory and Learning

- Once your child is out of post-traumatic amnesia, they will no longer forget everything from day to day, but they might still experience memory problems.

- While new information might be remembered immediately after it is seen or heard, your child might have trouble remembering it after some time has passed. As above, written information may help. Simply repeating the instructions several times may also be of benefit.
- Keeping a diary with appointment times, or having routines can help your child with schoolwork, homework and appointments.

Word Finding

- Your child may find it difficult to think of the right word to use (that feeling of a word being "on the tip of your tongue"). They might use a vague word (like "thingy" or "it"), talk less, or have lengthy pauses in conversation and take a long time to say what they mean. You can help by starting the word for them, or talking around the subject to get them to the right word.

Problem Solving, Planning and Decision Making

- Your child might have difficulty holding pieces of information in their mind if they have to make a decision, solve a problem or organise an activity that is not straightforward. One way to help can be to break down problems into several steps and help your child work through each step.

A change in your child's thinking abilities might be noticeable to you in the early stages after brain injury. However, problems can improve rapidly in those early stages and there is little

PARENTS' TIPS

- The doctors can show you basic first aid tips. There are formal first aid courses run by St John's Ambulance service, which you can ask about.
- Gentle massage can help relieve skin pressure for your child in the bed and chair.
- More information such as videos or fact sheets are available from the team on specific medical problems, such as epilepsy or dysautonomia.

point in measuring skills too soon if they will have changed again in a short time. When changes in thinking and learning skills have become more stable, a neuropsychologist can assess any changes or problems that remain, so ways of dealing with them can be discussed.

Neuropsychological assessment

usually happens after discharge and once your child has had time to return to school. The neuropsychologist may meet with you to discuss what you have noticed since the injury and they might ask your child to do activities and answer questions that can help with the assessment.

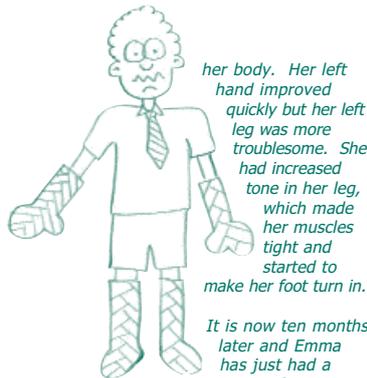
Neuropsychologists assess a child's thinking and behaviour through interviews, observation and formal testing. It is important we have a good history of your child's development so that the neuropsychologist can estimate any changes, and what needs to be done to help.

Testing involves a range of activities like puzzles, drawing, blocks, answering questions and remembering things. It covers areas such as general intellectual ability, memory and learning, attention and concentration, language, problem solving, and organisational skills. These tests allow your child's skills to be compared to other children of the same age and identify strengths and weaknesses in your child's thinking and behaviour. The neuropsychologist can help guide your child back into the school system by helping to identify suitable school options and suggesting strategies to maximise their education.

PHYSICAL CHANGES FOLLOWING BRAIN INJURY

Your child may have physical changes after their injury. These can range from a mild disturbance in balance through to difficulties with walking, or moving their arms. Although improvement in physical function almost always occurs, some children are left with long-term physical changes. These can lead to frustration for your child at being unable to do their activities of daily living such as eating, dressing, and washing. The Rehabilitation team will be able to help your child with these problems, and encourage you to be part of this process.

My 4-year-old daughter Emma was involved in a car accident just after Christmas. She fractured her skull, which was considered a serious head injury. I was told that she would have some neurological deficits and that she might not be able to walk or talk. She stayed in intensive care for 3 days and was then taken to the ward for a further 7 days. The staff in the Intensive care unit were fantastic. They always included me in Emma's care, which was beneficial to me during those trying times. When Emma spoke, it was a great relief because I didn't know if she would be able to, however due to her injury she had weakness down the left side of



her body. Her left hand improved quickly but her left leg was more troublesome. She had increased tone in her leg, which made her muscles tight and started to make her foot turn in.

It is now ten months later and Emma has just had a series of injections called Botulinum toxin into her tight muscles. This weakens them so that her foot turns back out again enabling her to walk more naturally. She had to have a plaster cast on for two weeks to make sure that her muscles had a good stretch. She is back at preschool and is happy and has lots of friends. At this time she has shown no signs of any learning disabilities and will start school next year.

Weakness and changes in muscle tone

Muscle tone refers to how a muscle feels when it is moved and varies from person to person. The brain controls muscle tone by sending messages via nerves to muscles. When there is damage to the brain the signals are interrupted and the tone can become abnormal. When tone is increased the muscles are stiff and hard to move. This is referred to as *spasticity*. Tone can also be decreased and cause the muscles to be floppy. Most commonly, with a brain injury, one side of the body may be affected. This is called

hemiplegia. If both arms and legs are affected this is called *quadraplegia*.

Most physical recovery usually occurs in the first 12 months following injury. This is when intensive therapy input can most benefit your child.

Children with spasticity may develop tight muscles, leading to joint stiffness and less ability to move in the normal way. When tight muscles are left untreated, they may become fixed in an abnormal position. This is known as *muscle contracture*. A goal of rehabilitation therapy is to prevent this from occurring.

Coordination and balance

After brain injury, movements can become jerky or clumsy. The part of the brain most involved in coordination of movement is the cerebellum, and the movement disorder associated with this is *ataxia*. Adaptive equipment may be used to help your child if they have balance problems.

Change in sensation

Children with brain injury may have problems with how they perceive sensations such as touch, pain and temperature. They may also have a decreased awareness of the position of their arms or legs. In some cases, the child is at risk for injuring themselves. For instance, by burning themselves on a hot pipe because they have lost temperature sensation. The team will give suggestions for what can be done to help with sensory loss and improve safety for your child.

What sort of physical recovery can I expect for my child?

Physical recovery is variable and unpredictable, but there are nearly always improvements with time. Physical recovery usually occurs more rapidly than cognitive (thinking) recovery and often happens within the first twelve months following an injury. Things that can help in physical recovery include active rehabilitation and family support.

How does the team help with your child's physical problems?

The *physiotherapist and occupational therapist* will help your child in their physical recovery, but the participation of the family in therapy sessions is important so you can continue the exercises at other times. After brain injury, children become easily fatigued and so benefit from regular short bursts of therapy.

During therapy sessions your child will learn motor skills such as standing and walking in the correct way. Apart from sessions in the gym, your therapist may use other techniques such as casting/splinting, hydrotherapy and the tilt table.

Serial Casting

A part of the therapist's role with children who have a brain injury is one of prevention of problems. This is particularly so in regards to your child's muscles.

Muscles tend to become short when they are held or are pulled into the same position for long periods. This can occur when a child is lying still in bed, for

instance in the intensive care, or when there is abnormal tone in a muscle.

The muscles that are particularly prone to shortening are the calves, thighs, hips, arms and shoulders. Muscles can be prevented from becoming short by positioning the child so their muscles are lengthened, for example with splints. Gentle stretching exercises can help keep the joints from becoming stiff.

Therapists will use casting to position muscles in a lengthened position. This is done using soft padding, plaster of Paris and/or fiberglass to provide a stronger support. The cast may be complete (that is, wrap right around the limb) and left on for a number of days, or may be a split cast, which can be applied and removed at regular intervals. A lighter plastic splint may be considered for longer term use.

You may wish to ask your therapist for ideas on how you can help stretch your child's muscles when the cast is not on your child.

Chest physiotherapy

Children who have had a brain injury may get chest infections more often, particularly in the early stages. Physiotherapy for the chest aims to help remove secretions from the lungs and helps with chest infections. To do this the physiotherapist may pat over the chest as the child breathes out, and turn the child to help remove the secretions.



Hydrotherapy

Some children will benefit from having part of their therapy treatment in water. The warmth and buoyancy of the water can help relax tight muscles and move stiff joints, and can sometimes assist a child with movements they would not be able to do on land.

Tilt table/Standing Frame

The tilt table/standing frame is a piece of equipment that may be used during your child's rehabilitation. Your child lies on their back, with their feet supported on a footplate. Straps are used to support your child's knees, hips and trunk. Your physiotherapist will gradually raise your child into a standing position.

The tilt table has many benefits for children who have difficulty standing on their own. Being in an upright position may increase alertness. Gravity also has a positive effect on swallowing, digestion, and breathing. Standing in a tilt table helps to maintain the length of muscles in the legs.

Maximising Independence

The occupational therapist assists your child to be as independent as possible in every day activities such as dressing and feeding and advises on equipment and any modifications that may be required. They may be involved in several of the activities already mentioned above, such as serial casting for tight muscles of the arms. They may also help with the discharge process by making school and home visits to check how easy it is to get into your house and

if any changes need to be made. The occupational therapist may also be involved with areas such as driving and transport, writing, other classroom activities, and computer equipment.

PARENTS' TIPS

- Try to give your child a daily routine. An updated timetable is available each Monday morning for therapy and appointments.
- Part of the routine is rest. Keep visitor numbers down, and ensure that therapy, school and play times don't use up rest time.
- Recognise the amount of effort your child will use in doing simple daily activities. Your love, support and encouragement for these activities are invaluable.
- Be involved in therapy sessions – this will enable you to continue with the therapy for your child outside of the session.



FEEDING DIFFICULTIES

Following a brain injury, some children may have difficulties eating and drinking. This is common early in their recovery and can be due to agitation, fatigue, or damage to parts of the brain which co-ordinate swallowing.

What signs indicate that my child is having difficulty with feeding?

- Coughing or choking whilst eating or drinking.
- Gurgly voice when eating.
- Slow swallowing or chewing of food.
- Dribbling.
- Noisy breathing during or after meals.
- Distress or avoidance of food during mealtimes.

It is important if you notice any of these things happening, to tell a team member as eating and swallowing problems may lead to dehydration, weight loss or food going down the wrong way (into the airway). If this occurs, your child may be referred to the speech pathologist to make further assessments and recommendations.

A feeding assessment aims to see how safely your child can eat and swallow and may include:

- Testing the muscles that are used for eating and swallowing (tongue, lips, jaw and throat).
- Giving your child a small taste of food and drink of different consistencies e.g. pureed or mashed food.

It is common for children to start eating mashed or soft foods and thickened drinks in the early stages of recovery. These are easier and safer for them, and help to stimulate a good swallow. They may then progress to more normal food consistencies as their swallowing improves. A small number of children who have ongoing swallowing problems may benefit from getting extra nutrition via a feeding tube. This would be discussed with you if the need arises.

What can I do to help my child's feeding?

- Feeding your child only when they are alert and sitting upright.
- Reducing distractions to help concentration when feeding.
- Reminding your child about the steps of feeding, e.g. close your lips, chew, swallow, cough, show me its all gone.
- Keeping your child upright for 15 minutes after the meal.

LANGUAGE & COMMUNICATION

Children up to the age of eight, but particularly those under five years, are in the process of acquiring and consolidating their language skills. Brain injury may compromise some of the skills that have already developed and also affect future language development.

The speech pathologist, as well as other team members, will be able to suggest the best ways to deal with any problems that do occur.

Speech and language can be affected in several ways after an acquired brain injury. It is important to explain the difference between these terms:

Speech is the production of speech sounds. After brain injury, your child may have problems with vocalisation, or with slurred, imprecise speech. *Language* is the understanding and use of words and sentences.

It is important to note that your child's speech, and understanding and use of language, may change at different times, and is directly affected by fatigue. In the early stages it is common for children to understand a simple conversation, but not talk spontaneously or reply to questions. At this stage it is important to understand that your child is not being lazy or difficult, but needs time to rest and recuperate. It is advisable to talk with the child but not expect a spoken response.

Please discuss the following suggestions with your speech pathologist and ask which are relevant for your child.

- In the earlier stages of recovery, always assume that your child understands conversation even if you can't see a response. Children are reassured by hearing a familiar voice.
- Say your child's first name to gain attention and use short, simple spoken information. Try to avoid too many people talking to your child at the one time.

- Give your child enough time to think about what you have said - say a short phrase then pause for several seconds before you say the next phrase. You can also use visual information to help them understand what is said. For example, you can hold up a cup while you ask if your child would like a drink.
- If your child is having difficulty communicating it is very frustrating to be asked questions which are hard to answer. If you wish to ask a question, try to give a choice of two responses. For example, ask 'Do you want a banana or an apple?' Asking a two-choice question increases the likelihood of getting a response and decreases frustration for children who are having word finding problems.

How can the speech pathologist help my child?

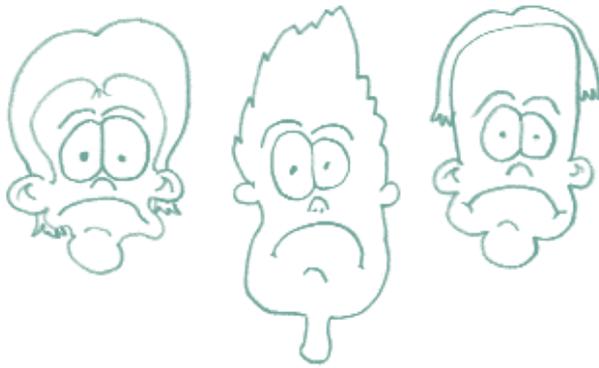
An early goal will be to establish a consistent yes/no response that can be understood by family, friends and staff. If your child is not yet talking this could be with a head nod, or a 'thumbs up/down' gesture, or a picture symbol.

As your child's health improves and they become stronger, speech therapy sessions may become longer and more focussed and are often held in a clinic room away from the ward.

After discharge from hospital, a review date may be made for formal assessment. Observation, conversation and a range of tests are used to evaluate your child's speech and language abilities. Tests may include understanding of long or

complex instructions, vocabulary, and ability to take part in conversation, or re-tell a story. Results of these tests are discussed with each family and, when appropriate, used to liaise with the school to help ensure that your child receives appropriate support.

Test results are also used to help determine areas for intervention. If your child needs ongoing therapy the speech pathologist will organise this for you with local services.



What are some of the long-term changes in language?

Talking and understanding language is dependent on other cognitive skills. For example, a child with reduced memory often has difficulty understanding long spoken instructions.

Reduced attention span may lead to difficulty in concentrating on conversation. There may be difficulty with staying on topic or responding adequately to what has been said.

The speech pathologist will discuss your child's specific difficulties with you, and talk about ways that you can help. If appropriate, and with your permission, your child's preschool or school will also be contacted to discuss a suitable language program.

NOTES
