



This book is a joint effort of:

the children's hospital at Westmead



MOTOR ACCIDENTS AUTHORITY

SYDNEY CHILDREN'S HOSPITAL

"My Playground" by Dinda

# 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.

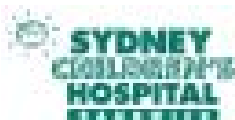
Information in these booklets is based on the team's experience, literature published by other organisations, and conversations with families and children with brain injury. It is intended as a guide, and families should seek professional advice as needed. Please note that some of the information provided may become outdated over time.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

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## BOOKLET 1

When a child has been admitted to Hospital with a brain injury, there may be many different people who are involved in their care. Parents often have many questions about what is happening.

Although staff will speak with you, some families find it useful to have written information to reinforce what has been said. We hope that these booklets will help you to better understand what is happening, so you can feel more involved in your child's rehabilitation program. You may wish to pass on the booklets to family or friends to help answer some of their questions as well.

At the end of some of the sections, we have included tips from other parents, which you may find useful. The information in these booklets and the tips are meant as a guide. In producing these booklets, we have considered the needs of a wide variety of families. Some families need a lot of detailed information early, whereas others prefer information later on. If you find the information too detailed at this time, you can leave it or go through sections with a team member.

The booklets will be updated over time. Therefore we would value your comments and suggestions about the usefulness of the content. You can talk to a member of your Rehabilitation team or complete the suggestion sheet at the back of this booklet.

1 The five booklets that are available include:

### 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 brain injury.

### Booklet 4:

Family, emotions and going home.

### Booklet 5:

Medico-legal advice, teenagers and contact numbers.



## WHEN DOES REHABILITATION START ?



Once your child is medically stable, the Intensive Care, Neurology or Neurosurgical doctors may ask the Rehabilitation Team to become involved in your child's care. In this way, rehabilitation is the bridge that links your child's early medical care to making plans for their eventual return to home and school. After a time in intensive care, your child will go to the ward where rehabilitation may continue.

- Liaising with schools, and services in the community that may be needed when they go home.

Some of the areas that may be assessed by the Rehabilitation team include dressing, sitting and walking, communication, cognition (thinking) and behaviour. Rehabilitation also involves helping families to deal with the shock and sadness they have experienced through their child's injury or illness. A program is worked out with the family so they can help their child as much as possible. By commencing rehabilitation early, the best results can be achieved to help your child return home and to the community as quickly as possible.

### What are the goals of rehabilitation?

The goal of rehabilitation is to help children and adolescents make the best possible recovery in all areas of development. The process will be different for every child, depending on the problems the injury may have caused, and the child's age and stage of development. Your child's rehabilitation program will help make the most of their body's natural healing abilities so they improve as quickly as possible. This involves:

- Preventing problems from occurring during the recovery stages.
- Helping to restore skills that may have been affected.
- Teaching ways of compensating for skills that may have been affected.
- Helping your child to understand some of the changes that have happened.

### What role does the family play in rehabilitation?

Your child and family are the most important members of the Rehabilitation team. Staff will spend time teaching you about aspects of the rehabilitation program and how you can be involved. Nursing staff will also encourage you to be involved in the daily care of your child. Gradually you may feel you want to do more and more. It is important to let staff know what you would like to do.

Therapists will see your child for regular sessions, based on what your

child needs. A weekly timetable may be written for each child so families know when these sessions will be. The therapists encourage parents to attend sessions and to be involved in the therapy program for their child. The time you spend with your child doing family activities such as going for a walk or playing games, is also an important part of the recovery process.

Families are also able to take part in the planning of the program by being part of family meetings. Even in the early stages, we like to plan with you about the kinds of things that need to be achieved for your child to be able to go home.

Once you meet the team who will be involved in your child's care, you may find it useful to refer to the

information within this series of booklets to gain a better understanding of the different areas in which rehabilitation occurs.

### Who are the members of the Rehabilitation team?

The Rehabilitation team consists of different professionals who have their own area of expertise but who work together. The team sees children who have been in motor vehicle accidents or have had sporting injuries, falls, a stroke, brain tumour or infection such as meningitis/encephalitis. The role of the team members may vary in different hospitals but the most important similarity is that the team works closely with the family.

## REHABILITATION DOCTORS

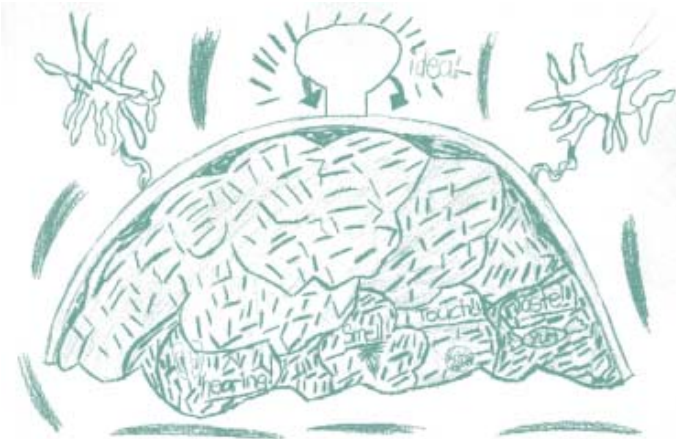


As soon as a referral is made to the Rehabilitation Team, a Rehabilitation Consultant is allocated to your child's care. This consultant is a paediatrician who specialises in rehabilitation. Initially, there may be other medical teams involved in your child's care and it is important that these teams communicate with each other. The Rehabilitation Consultant may become the main doctor who manages your child's care in hospital, once your child needs less help from other medical teams.

The first contact you have with the rehabilitation team may be by the Rehabilitation Registrar. This doctor works closely with the Rehabilitation Consultant to make day to day decisions about your child's care.

Other roles of the doctors are:

- Managing any medical problems your child may have as they recover from their illness or injury.
- To explain the impact and likely outcome following the illness or injury.
- To consult with other specialists involved in your child's care to ensure that the best possible plan for rehabilitation can be made.
- To keep your local doctor (and/or paediatrician) informed of progress by letter or phone contact.
- Doctors will also provide families with written summaries from family meetings and assist with completing forms such as the disability allowances, parking permits, and supplying medicolegal reports to solicitors and insurance companies.
- After discharge from hospital a Rehabilitation doctor sees children for follow-up in the outpatient clinic.



an introduction to the brain injury rehabilitation team



an introduction to the brain injury rehabilitation team

## NURSING UNIT MANAGER

The Nursing Unit Manager (NUM) works Monday to Friday from 8.00am – 5.00pm and is responsible for the day-to-day running of the ward. When the NUM is not on duty, a nurse in charge of the ward takes on the role.

Another responsibility of the NUM is to make sure that all children and parents on the ward are being cared for in the best possible way. The NUM visits the family regularly and the family can speak to the NUM if they have any issues that they need to discuss. The NUM is also able to contact any member of the team if there are problems that need to be sorted out.

## REGISTERED NURSES

Nurses on the ward are responsible for assessing the children's general condition and providing care that helps the child to become as independent as possible during their rehabilitation. They work with the rest of the Rehabilitation team to make sure that the programs that have been decided on are carried through. A nurse will be allocated to care for a child over 3 shifts per day.

- The morning shift starts at 7.00am and finishes at 4.00pm.
- The afternoon shift starts at 2.00pm and finishes at 10.30pm.
- The night shift starts at 10.00pm and finishes at 8.00am.

The nurse caring for a child will "hand-over" care to the nurse on the next shift and bring them up to date with any changes that have happened during their own shift. It might seem that it takes a little longer for things to be done at these times.

Nurses are responsible for procedures such as giving medications, checking temperature and pulse, and completing a record of fluid and food intake. Many parents are eager to begin washing, dressing, feeding, and generally caring for their child. It is important that nurses know what parents feel comfortable doing so they can work together with them. Nurses can support and assist families, by teaching specialised care that some children will need after a brain injury.

There will be times when you need to attend to other family matters and spend time with other members of your family. Let nursing staff know of your plans.

## CLINICAL NURSE CONSULTANT

This specialised nurse works as a coordinator of the inpatient Rehabilitation team, to bring together the teams skills so that your child's daily timetable suits their level of recovery and that goals for going home are being reviewed. The Clinical Nurse Consultant is able to provide specific education and support to families about the special needs of their child who is receiving rehabilitation. They usually arrange the meetings which are held to plan the rehabilitation program. They also act as a resource person to assist ward nurses in planning specific nursing care for your child such as bladder and bowel care. As discharge is being planned, the Clinical Nurse Consultant will help your family organise the different services and appointments that will be needed once your child leaves hospital.

## OCCUPATIONAL THERAPIST

The Occupational Therapist assists your child to be as independent as possible in every day activities. They work closely with other members of the Rehabilitation team in assisting your child to relearn skills that may have been affected.

Initially the Occupational Therapist may be involved in:

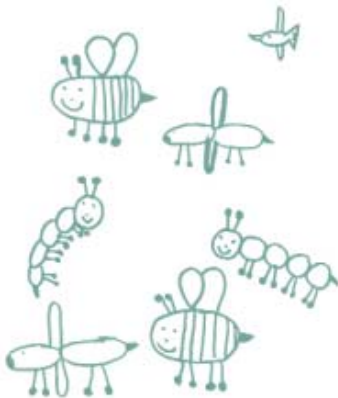
- Hand splinting and upper limb activities if there is a concern that your child's muscles are getting tight.
- Providing supportive seating and equipment.
- Post Traumatic Amnesia testing if your child is confused or having difficulty remembering day-to-day events.

As your child improves, the Occupational Therapist may focus on:

- Developing independence in self-care, including bathing, toileting, dressing and eating. Equipment is provided if necessary.
- Strengthening and increasing the use of the arms if they have become weak.
- Helping your child to get back into a daily routine. This may include monitoring your child's ability to make safe decisions, plan ahead, and pay attention.

As discharge from hospital approaches, the Occupational Therapist may organise a home or school visit to see if equipment needs to be fitted or modifications organised.

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## PHYSIO-THERAPIST

Physiotherapists specialise in managing the physical difficulties your child may have. Their role will depend on the stage of your child's recovery.

Initially, in intensive care, this may include:

- Chest physiotherapy.
- Prevention of future problems by the use of splints and plasters to the lower limbs.

Once your child is well enough, the Physiotherapist will help your child to relearn any motor skills they may be having difficulty with. This may involve:

- Support from a tilt table or standing frame to help them stand up.
- Strengthening and retraining to help sit, stand, and walk.
- Hydrotherapy.
- Exercises to practice between therapy sessions.



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## MUSIC THERAPIST

The Registered Music Therapist works with the Rehabilitation team to plan musical experiences that will provide opportunities to affect changes in your child's social, emotional, physical and cognitive recovery. Musical techniques, such as singing, instrument playing, song writing, music listening, improvisation, or music and movement, are combined with therapy to address each child's individual needs.

## SPEECH PATHOLOGIST

The Speech Pathologist usually becomes involved with your child in the early stage of their recovery.

- Initially this may be to check how well your child is able to eat and drink. The Speech Pathologist will also discuss this with the dietitian to ensure that the correct food is sent for your child at mealtimes.
- If there are any problems with these areas, the Speech Pathologist will teach you ways to make sure your child swallows safely.
- As your child recovers the Speech Pathologist can assist your family in looking for ways of encouraging your child's communication by

helping them understand what is being said and how they are able to express themselves.

- At later stages of recovery, the Speech Pathologist will assess your child's speech and language skills further and provide therapy to assist in improving these if necessary.

## PLAY THERAPIST

The role of the Play Therapist is to provide positive experiences for your child so that they are motivated to take part in their rehabilitation program and regain their skills. Through play, your child will be able to express their feelings and emotions about being in hospital. The Play Therapist can then plan a program to meet the needs of your child, either on their own or as part of other groups.

Some of these activities may include:

- The use of books, stories and puppets to help with language development.
- Using simple games, art, play, and cooking to assist in developing cognitive skills.
- Preparing your child for any new procedures which may cause them to be scared.
- Joining in groups that will encourage your child to be independent and interact with other children.

## NEURO-PSYCHOLOGIST

The Neuropsychologist is concerned with looking at how brain injury may have affected your child's thinking (cognition) and behaviour. Assessment may be done by interviewing you and your child, by observing their behaviour, and by special testing. This testing usually occurs once your child has left hospital.

The assessment covers areas such as:

- General intellectual ability.
- Memory, attention and concentration.
- Ability to make sense of information.
- Planning and organisational skills.
- Problem solving abilities.
- The ability to behave in the right way in different situations.

This information is used to assist in the planning of your child's rehabilitation program, for example when decisions regarding school placement are being made.



an introduction to the brain injury rehabilitation team

## CLINICAL PSYCHOLOGIST

The Clinical Psychologist specifically helps children cope with the effects of their illness or injury. Some of the problems children commonly experience include feelings of anxiety or depression, and they may show difficult or aggressive behaviour, post traumatic stress, or sleep disturbance. The Clinical Psychologist can help your child to identify and change the thoughts, attitudes and habits that cause these problems and to learn effective ways of coping with the challenges they face.

## DIETITIAN

The Dietitian gives advice about nutritional needs of your child and decides on the amount of food and additives (such as vitamins) that may be needed during their recovery. They may also be involved long-term for children who develop problems with their weight.

## SOCIAL WORKER

Having a child in hospital can be a stressful time for you and your family. The rehabilitation Social Worker meets with all families who have a child receiving rehabilitation. Due to the nature of the injuries and length of hospitalisation, your child and family members may experience a range of emotions that can be hard to deal with. The Social Worker can discuss issues such as:

- The traumatic effects of illness or accident on your child and family.
- Coping with a long term illness and hospitalisation.
- Adjustment to loss and change.
- Concerns about your child's development and behaviour.
- Helping your child to manage fears and worries about treatment and procedures.
- Assisting your child to regain some control over their situation through techniques such as relaxation and development of self esteem.

- Behaviour problems in your child.
- Accessing hospital and community services.
- Information and advice regarding financial benefits, housing, accommodation and medico-legal issues.

## CO-ORDINATOR FOR THE BRAIN INJURY REHABILITATION SERVICE

The Co-ordinator is involved "behind the scenes" in ensuring the smooth running of the brain injury service. This includes contact with a range of other agencies such as the Department of Education and Training, NSW Department of Health, the Brain Injury Association of NSW and other Brain Injury Rehabilitation Programs (BIRPs).

## CASE MANAGER

The Case Manager forms part of the outpatient team that may become involved with your child's care once they are discharged.

They form the link between you and the community and will work with your family to look at areas of need such as:

- Co-ordinating ongoing appointments.
- Assisting with your child's return to school.
- Ongoing therapy.
- Home support, respite, and community services and activities.
- Liaison with insurance companies. If your child has an insurance claim, your Case Manager is required to submit a plan to the insurance company describing your child's progress and goals.

Contact may be made by phone calls, home visits, and attendance at appointments at the hospital. The length of time your child is case managed depends on your child and family's needs.

## PRACTICAL TIPS

- Write questions down before meeting with the doctor or team and then write down answers so you can review them later.
- Always ask for further information if you are unsure about what has been said.
- Ask the social worker about parking subsidies and other practicalities at the Hospital. (e.g. accommodation, meal tickets)
- Ask the social worker about what to do if bills are sent to you.

## SCHOOL TEACHER

A teacher from the hospital school will work with school-aged children as part of their rehabilitation. In the early stages of your child's recovery the Teacher may see your child on a one-to-one basis. Later on your child will be encouraged to go the hospital classroom. With your permission contact will be made with your child's school to gather information about their schoolwork before they were admitted to hospital. This assists in planning for your child's return to school once they leave hospital. A specialist school counsellor may also be involved in making suggestions about your child's return to school.

