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the
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 SYDNEY
CHILDREN'S
HOSPITAL
RANDWICK

"Ayers Rock" by Ben Smith

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 Please note that some of the information provided may become outdated over time.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



Being a teenager is a time of testing new ground, risk taking and self-discovery towards independence in adulthood. Young people with a brain injury also need to move through this period of growth. The nature of a person's injury can have an impact on this process. For some young people the process will be very similar to other people their age, for others there will be major issues to face in relation to balancing the quest for independence with physical and cognitive abilities.

Hello, my name is Daniel and I was involved in a car accident when I was two years old. I went through many of the procedures described in these booklets and then some. But with the help of my physio, OT and speech therapist and lots and lots of hard work, I got back on my feet where I was able to carry the Paralympic torch.

I had a great time at school, I took part in a TAFE program and work experience. I learnt to swim and now enjoy snorkeling, rowing, karate (a 5th Kyu blue belt), and I love to ski.

I left school and found work in a great company. I will also take part in an exciting new independent living skills program. After leaving hospital and school, I am looking forward to bigger and better things to come.

What are some of the emotional issues that are important for young people who have a brain injury?

Most teenagers have emotional ups and downs, and parents often find this the most trying period of their child's development. Sometimes emotional difficulties are harder to handle in young people who have had a brain injury. Depression is common in this age group, and young people who face the additional difficulties associated with coping with a brain injury may be more vulnerable. You may find it useful to talk with someone who has expertise in issues to do with adolescence. It could be helpful for you and your child to have advice from a psychologist, social worker or psychiatrist as well.

You are not alone in facing these issues. There is a wealth of information and experience relating to different aspects of growing up.

What about driving after a brain injury?

Driving is an important rite of passage into adulthood, however for young people with a brain injury the process is different. Difficulties like limited attention, visual problems and the ability to make safe and quick decisions can affect driving ability.

When applying for a learners permit:

- Go to the Road Traffic Authority (RTA) and ask for a medical assessment (green) form.
- Take the green form to the Doctor on the Rehabilitation team, who will complete it and note whether you can drive in the usual way or they may suggest further assessment.
- We often suggest a driving assessment by an occupational therapist, who assesses ability to drive and can recommend driving modifications such as a spinner knob to drive one handed, or hand controls.
- As safety on the road is important sometimes we have the hard job of telling some adolescents that their medical problems will prevent them from driving.
- If your child is unable to drive, members of the team may assist in looking at other transport options (taxi vouchers, mobility allowance).

For further information, talk to your occupational therapist or doctor.

What about support towards the end of the school years?

Depending on the nature of a young person's injury, there are a variety of supports available for students in their later school years which help bridge the gap between school and tertiary studies. Some students are eligible for assistance with things such as

additional time for exams, using computers to write exams, special consideration for physical needs and so on. Some students are eligible for special consideration in relation to their final school marks and entrance to tertiary studies.

These issues need to be raised with the school in the first instance. Most schools have counsellors who can help with the necessary paper work. Your BIRP team members can assist with providing information to school.

What are the after-school options?

There are options for further education for people with brain injury after school. What may be appropriate depends on a person's interests and abilities. TAFE colleges have a range of programmes, including continuing education in literacy and numeracy, training for specific jobs and general interest subjects. Some young adults may wish to pursue tertiary studies at university. Universities and TAFE colleges have disability advisors who assist students in the transition from school. Information is available from them in relation to enrolment and assistance at university.

What about work?

It is important to start looking at work options before your child leaves school. There are numerous "vocational rehabilitation" services

that specialise in working with people with a brain injury. Different services can work with your school program to provide work experience that may lead to finding suitable work or training. These services can also assist in setting up TAFE, University, or other relevant courses.

For further information, talk to your doctor or therapists on the Rehabilitation team.

What are some of the important social issues during the teenage years?

3 ■ Belonging to a peer group is an important part of being a teenager. Some find this stage difficult to handle and feel that they do not fit in. It can sometimes be beneficial to link in with others who have had similar experiences. For groups see Northcott Society, Brain Injury Association, BIRPs (Sydney Children's Hospital, The Children's Hospital at Westmead, and Rural). You may need to encourage and support your teenager in making and maintaining friendships. For example: coming up with ideas of what to do and who to invite, and making sure venues and events are accessible and appropriate. The Rehabilitation team is also available to give talks to classes/teachers and other staff members.

Is sexuality still important after a brain injury?

Sexuality covers all our sexual thoughts, feelings, values, beliefs, actions and drives. It includes self-worth and desirability, giving and receiving affection and caring in personal relationships. A brain injury

may impair but does not eliminate these needs and feelings. For example, some young people with a brain injury may experience difficulty in developing or maintaining relationships and displaying affection appropriately. This is a difficult area for any parent. For information about how to address these issues, you can talk to a social worker, occupational therapist or doctor on the team.

Other resources include:

- FPA Health (Family Planning Association)
- The Northcott Society
- Sexuality Book, at The Children's Hospital at Westmead

What about drugs and alcohol?

Statistics indicate that young people are experimenting with drugs and alcohol at an early age. After a brain injury the physical implications of drug use are even more significant. Risks include causing further brain damage, increased risk of seizures, increased risk of another accident or injury, decreased effectiveness of medication and increased feelings of depression. If you are concerned about your child, talk to the social worker or doctor on the team.

What happens when your child moves into adulthood?

There are 13 Brain Injury Rehabilitation Programs across NSW. Two of those units specialise in children only. The remaining 11 are adult or adult/child services. Once your teenager leaves school they may be eligible to receive services from the adult brain injury team.

MEDICO LEGAL ASPECTS AND EXPENSES

Personal injury claims

If your child has been involved in a motor vehicle accident in any way, you may be eligible to apply for compensation under the Compulsory Third Party (CTP) Insurance Scheme. This could include if they were a

passenger, pedestrian, or bicyclist. There may also be compensation if your child was injured whilst in the care of others. The team will be able to further explain the details to help with this area.

Why should you lodge a claim?

Although the claims process may take many years, it is important to put in a claim as early as possible. This allows the team to plan for appropriate services and equipment when your child is discharged. This might include costs incurred by you to take your child to therapy (time off work and travel), as well as the therapy cost. Compensation monies might also pay for other services such as respite care. It is important to note that the care you receive from the team will be the same, whether there is a legal claim or not.

The team can assist you in lodging a claim. A claim form is available either through the team, a solicitor, the insurance company of the vehicle at fault or the MAA.

It is possible to lodge a claim by yourself. The Motor Accidents Authority (MAA) is the organisation that oversees insurance companies and the claims process and has a claims resolution service that can assist you with your claim.

Will a solicitor be necessary?

It is usually helpful to engage the services of a solicitor to lodge your claim. The solicitor should act as your advocate on legal matters and provide advice as to whether your claim should be pursued. They can then



also act on your behalf if liability is yet to be determined or if the insurance company denies liability. Your solicitor can also advise you on the amount of compensation your child is likely to receive.

What will it cost?

You should discuss this with your solicitor at the first meeting. The Law Society of NSW advises that many solicitors will provide a free initial consultation to discuss whether your case is worth pursuing for compensation. You should ask about this when making the appointment. Furthermore, some solicitors will meet ongoing costs themselves until liability has been determined, and then take their fees from the final settlement.

How do I choose a solicitor?

It is important you choose a solicitor who has special accreditation in personal injury. That is, a solicitor who is specialised in doing third party compensation claims. The Law Society of NSW can provide you with the name of a solicitor in your area who is accredited in personal injury. Contact The Law Society of NSW on 93737300.
www.lawsocnsw.acn.au

What if I have concerns about the claims process?

For children who are compensable, the insurance company may allocate a rehabilitation advisor. This person oversees the rehabilitation claims process. Your insurance company can advise you on who is involved and who to contact about your claim.

The Motor Accidents Authority (MAA) is the organisation that oversees all CTP insurance companies and the claims process. There are guidelines in place to help resolve difficulties. More information is available at the MAA by phone, fact sheets or websites (see resource list).

Children's Allowances

Centrelink provides two payments for carer's of children under the age of 16 years. These are the Carer Allowance and the Carer Payment.

- The Carer Allowance – this includes a health care card, and depending on the level of disability, a fortnightly payment. Eligibility for a health care card is based on the extra care and attention provided for the child because of their disability. Eligibility for the fortnightly payment is based on the way the child functions compared with the average ability of a child of the same age without a disability.
- The Carer Payment – this payment is for carers of a child under the age of 16 years, with a profound disability where intensive full-time care is provided at home. The care needs must be long term and provided on a daily basis. The payment may be paid in addition to some other social security allowances such as the carer allowance. The Carer Payment is an income support payment subject to the income and asset tests that apply to other social security payments.

Ask your social worker for the necessary forms or contact your local Centrelink office and ask for the

“Claim Pack”. For adolescents over the age of 16 years with a disability, the disability support pension may be applied for through Centrelink.

Advocacy associations

Following brain injury, families may need assistance in dealing with government and legal agencies. An advocate is someone who assists the family to communicate effectively with these agencies and other service providers. The Paediatric BIRP teams will provide advocacy for children with brain injuries. Other advocacy services include:

The Brain Injury Association of NSW *ph 02 9749 5366*

The Disability Council of NSW *ph 02 9230 1583*

The Multicultural Disability Advocacy Service *ph 02 9891 6400*

Parking stickers and other transport options

- Disabled parking stickers are available from the Roads and Traffic Authority. A form will need to be completed by your doctor. Prior to receiving the sticker, you should speak to the social worker about parking arrangements for parents of patients at the hospital.
- Mobility allowance – this is paid to those older than 16 with a disability who have difficulty using public transport. It is paid in addition to other benefits and is not means tested. If you wish to make an enquiry regarding public transport or make a complaint, call 131500.

- Taxi transport subsidy scheme – this is managed by the Department of Transport and provides half fare taxi vouchers up to \$25 per trip, for disabled persons who are unable to use public transport. Application forms are available from the social worker.

TIPS

- Ask the team what to do with any hospital bills that are sent to you.
- Lodge claims for disability allowances as early as possible as there may be delays in the time to the first payment.
- Ask the social worker about what transport options your child is eligible to receive.



CONTACT NUMBERS AND INFORMATION SOURCES

What numbers do I ring in an emergency?

- General Emergency *ph 000*
- Sydney Children's Hospital, Emergency *ph 02 9382 1430*
- The Children's Hospital at Westmead Emergency *ph 02 9845 0000*
- Your local GP *ph _____*

Who can I contact if I have concerns when my child comes home?

- Sydney Children's Hospital BIRP team *www.sch.edu.au ph 02 9382 1590*
- The Children's Hospital at Westmead BIRS team *www.chw.edu.au ph 02 9845 2132*
- Your Rural BIRP *ph _____*
- Your local GP *ph _____*
- School counsellor *ph _____*

- Case Manager *ph _____*
- Parent Advisory Committee *ph _____*

What other resources are available to families?

Information and support

- KidsNet Helpline for advice on sick kids. *ph 02 9845 2432*
- The Brain Injury Association (BIA): a statewide information and support service for people with brain injury and their families. The BIA has a newsletter, and runs groups and forums. Free membership. *ph 02 9749 5366 www.biansw.org.au*
- Brain Injury Australia: a national information and advocacy service for people with brain injury which provides a series of information booklets. *ph 02 6290 2253*
- People with Disabilities and Disability Complaints Service *ph 02 9319 6622 www.pwd.org.au*
- Hospital complaints (the patient's friend) via hospital switchboard.
- Carers NSW *ph 1800 242 636 www.carernsw.asn.au*
- MAA Motor Accidents Authority *ph 1300 137 131 www.maa.nsw.gov.au*

- Northcott Society *ph 02 9890 0100 www.northcott.org.au*
- Home and Community Care (HACC) *ph 02 9689 2666 1800 350 792 www.add.nsw.gov.au*
- Disability Information Referral Centre (DIRC) *ph 9375 1444 www.dirc.asn.au*

Local Services

- Your local library has a list of local leisure options and services.

Leisure Services

- NSW Sport & Recreation *ph 131 302 www.dsr.nsw.gov.au*
- Sailability: learn to sail club for people with disabilities and their families. *www.sailability.org.au*
- Sports Council for the Disabled: provide information on a range of sport and recreation services and facilities, and run a number of specialised programs for a range of abilities. *ph 02 9763 2455 www.nsw.disabilitysports.com.au*
- NSW Wheelchair Sports Association *ph 02 9809 5260 www.nswwsa.org.au*

Taking a break

- National Respite Service gets you in touch with a range of respite options in your local area and runs some respite packages. *ph 1800 059 059 www.health.gov.au/acc/carers*

The BIRPs:

A parent or other family member, as well as doctors and health professionals can make referrals to these services.

- Paediatric Brain Injury RehabTeam John Hunter Children's Hospital Lookout Road NEW LAMBTON *Hospital ph 02 4921 3932 Community ph 02 4921 5719*
- Hunter Brain Injury Service (Adult) 313 Darby St BAR BEACH 2300 *ph 02 4929 3100*
- Dubbo BIRP Po Box 974 DUBBO NSW 2830 *ph 02 6841 8559*
- Illawarra BIRP 8 Eyre Pl WARRAWONG NSW 2502 *ph 02 4276 4717*
- Liverpool BIRP (adult) Liverpool Hospital PO Box 103 LIVERPOOL 2170 *ph 02 9828 5786*

- Westmead BIRP (adult)
Westmead Hospital
Hawkesbury Road,
WESTMEAD
ph 02 9845 7941
 - Royal Rehabilitation Centre (adult)
PO Box 6
RYDE 2112
ph 02 9807 1144
 - Mid Western BIRP
Eric Sargent Drive
BATHURST 2795
ph 02 6339 5100
 - New England BIRP
PO Box 83
TAMWORTH NSW 2340
ph 02 6768 3346
 - South West Brain Injury
Rehab Service
PO Box 326
ALBURY NSW 2640
ph 02 6041 9902
swbirs.thekidsteam@swhs.nsw.gov.au
 - Southern Area Brain Injury Service
PO Box 274
GOULBURN NSW 2580
ph 02 4823 7911
 - North Coast Head Injury Service
(4 branches)
145 Laurel Ave
LISMORE NSW 2480
ph 02 6620 2111
- 39 Victoria St
COFFS HARBOUR NSW 2450
ph 02 665202856
- Shop 7 Port Pacific Building
Clarence St
PORT MAQUARIE NSW 2444
ph 02 6592 9645

Taree Community Health
Corner of Putney and High Sts
TAREE NSW
ph 02 6592 9645

Recommended websites

- www.tbidoc.com - devoted to the understanding of brain injury and the role of neuropsychology in identifying, and treating brain injury.
- www.biausa.org - lots of links to relevant sites and resources, family helpline, advocacy associations and a chat room.
- www.tbichat.org - chat rooms for caregivers, and children/adults with brain injury. They have a humour board (with jokes!) and you can create your own home page.
- www.headwayvictoria.org - lots of Australian information about head injury.
- www.sasquatch.com/tbi/ - allows you to email questions to experts in the field or add to someone else's question.
- www.comarecovery.com - information about coma recovery. Includes a help line.
- www.chw.edu.au/rehabilitation and www.sch.edu.au
The Children's hospital websites contain fact sheet, booklets and links on Brain Injury and other conditions

Recommended Reading:

- This booklet! There is a range of other information packages in the libraries at each hospital. Ask the team to show you where the library is.
- The Adult BIRPs produce fact sheets on Brain Injury, which are useful for teenagers and young adults.
- Head Injury: The Facts: A Guide for Families and Care-Givers (Oxford Medical Publications).
- Commonwealth Rehabilitation Services Fact Sheets on Brain Injury

Recommended videos

There is a series of videos explaining brain injury including interviews with children and their families. Ask the teams at Sydney Children's Hospital and The Children's Hospital at Westmead to see them when you feel you are ready.

Seminars, support and education groups

Various groups throughout the year run these. The Brain Injury Association is generally informed of which sessions are being run at which locations.

TIPS

The best resource the BIRPs have to offer is the expertise of their staff. They are there to help you and your child manage whatever changes may have occurred as a result of the injury. Ask the staff for advice about where to go next if you are unsure of where to get help.



