2. Especially for Parents Contents

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About the second edition...

This booklet is one of a series of "Fact Packs" that were developed by The Kids' Team at South West Brain Injury Rehabilitation Service (SWBIRS) in Albury over many years. The creation of the second edition of Fact Packs is intended to provide updated content designed to enhance the clinical usefulness of these resources.

Our aim was to collate some practical, user friendly material that has been found to assist families and educators in our work and in the research literature. We hope that we have developed a set of resource booklets containing a range of referenced, user friendly strategies and ideas relating to common issues that arise after an acquired brain injury (ABI). Introducing any new ideas or strategies will take time, patience and persistence. The advice from countless parents would be "hang in there."

It is intended that the Fact Packs will be used in conjunction with service provision by The Kids' Team or other ABI health professionals.

Some of the material included has been adapted from textbooks. Some has been developed by team members and much has been developed by the educators, rehabilitation workers and families supporting the children we see. Wherever possible, we have obtained permission to use the resources included

in the book. Please advise us if we have left something out!

To keep our material clear, we have used "he" to refer to the child with ABI throughout the Fact Packs. This reflects real life for us, too, as the majority of the children with whom we work are boys!

We extend thanks to the **NSW** Department of Health who provided the initial funding for this project. Without this funding, the development of the Fact Packs would have been an idea that remained trapped in the minds of several enthusiastic but busy ABI workers. Finally, we are very grateful to all the Kids' Team members past and present, in addition to all the parents, teachers, school counsellors, students, therapists and ABI workers whose wisdom, energy, creativity and support has contributed to the development of these resources.

The eight Fact Packs in this series include:

- Achieving Goals
- ♦ Behaviour
- ♦ Choosing a School
- Especially for Parents
- ♦ Heads Up on Brain Injury
- ♦ Siblings
- Study Skills
- ♦ Teachers and Aides

We hope you find the Fact Packs useful. If you have ideas, resources, or material that could be included in future editions, please let us know!

The Kids Team SWBIRS

Dear parents,

When your child has sustained an acquired brain injury (ABI), you usually receive lots of information. It is quite a task to read it all, take it in and decide what is relevant for your child.

There are certainly a lot of good general ABI resources available, some of which are listed in the 'Useful References' section at the end of this booklet. One particularly good book is called ABI: The **Facts** (5th edition). It is produced by Synapse, the Brain Injury Association of NSW, and was completely revised and updated in 2016. The book provides a comprehensive and practical introduction to understanding and responding to ABI (email info@synapse.org.au to order a hard copy).

Unlike the Synapse book, this Fact Pack was not designed to provide general information about ABI; instead, the focus is on the specific needs of parents. We hope to provide you with information and practical tips on how to deal with some commonly encountered situations when living with children with an ABI. This Especially for Parents Fact Pack actually arose from a weekend held for the families of children with ABI. A group of parents met together and talked about what helped, what didn't, and what would make a difference. They talked about "What they know now, that they wished they'd known then".

Within the following pages you will find some of their ideas and strategies. It is certainly not intended to be an exhaustive, or exhausting document. Rather, we hope it will be a handy source of ideas, encouragement and hope.

Please let us know about other resources and ideas that you think would be useful to include in future editions.

The kids' team

South West Brain Injury Rehabilitation Service

A general overview

What is an acquired brain injury (ABI)?

An acquired brain injury (ABI) is an injury to the brain that occurs after birth. There are various causes of ABI which generally fall into two main categories:

Traumatic Brain Injury (TBI) (where an external force is applied to the brain)

- Motor vehicle, motor bike, bicycle, and pedestrian accidents
- Assault
- Falls
- Non-accidental injuries/abuse
- Sporting accidents
- Gunshot wound

• Non-Traumatic Brain Injury

- Strokes
- Tumours
- Infections
- Hypoxia (lack of oxygen)
- Poisoning
- Drugs/Alcohol

What are the effects of an ABI?

The effects of ABI vary greatly from person to person. It depends on factors such as the particular part of the brain that is injured, the seriousness of the injury, the treatment and support the child receives after the ABI, the child's stage of development and learning prior

to the injury, and other factors including general health and personality.

An ABI can result in changes to a range of areas, including a child's physical, cognitive (thinking), communication, behaviour, or emotional abilities. These changes can be temporary or permanent, and some may not show up until some years after the initial injury, as the child develops and is challenged to learn more complex skills and tasks.

An ABI is often referred to as a hidden disability because the effects of the injury are not always physically obvious. For example, cognitive abilities such as memory, abstract thinking, attention and judgment can all be seriously and permanently affected without the presence of any physical injuries.

The recovery process – will my child get better?

Recovery from an ABI is hard to predict accurately. You will probably extremely frustrated when you ask "how well is my child going to recover?" and you are told "We don't know". Parents often look years ahead and want to know what the future holds for their child, however it takes time to tell how serious an injury is and what the long term effects are going to be. It may not be clear, particularly in the early stages, what problems the ABI has caused, and it can be difficult to predict how much a child will recover, and how quickly. Even when the picture becomes clearer, it predict which difficult remains to problems will get better and which may persist. Advice from other parents is to take one day at a time, always look at the positives and focus on what your child can do.

Generally speaking, whilst every person's recovery is unique, there is often a general pattern of recovery following brain injury.

The greatest improvement is generally observed in the initial period following the injury. A period of rapid progress is usually seen in the first 6 months after the brain injury, with improvements often continuing to occur over the next 6-12 months, although the rate of progress becomes slower.

It is important to remember that recovery can be a long process, and can continue for many years following a brain injury.

The impact of an ABI on the developing child

Brain development is a complex and lengthy process that continues well into early adulthood. Consequently, injuries to the brain that occur in childhood will affect the typical trajectory of brain development. This effect may be in the form of disruption to ongoing development and/or difficulty with the future acquisition of skills.

For example, a child may find it more difficult than an adult to compensate for their loss of certain skills following a brain injury, as they typically have a smaller store of well-learned skills to draw upon and use in their place.

In addition, an 'injured' brain may find it harder to learn and to develop abstract thought processes. A child who is less able to learn may be unable to keep pace with their peers. As such, difficulties may not become evident until that time when their lives demand a particular skill. This is often referred to as the phenomenon of 'growing into a deficit'.

For example, a child may initially show minimal effects of their brain injury when they are younger. However, as they get older and the environmental demands increase, they may fail to make age-appropriate developmental gains, and difficulties begin to appear.

Therefore, a key component of rehabilitation in children is monitoring the child's (re)-acquisition of function after brain injury.

Preparing for transitions

Times of transition can be tricky for all children but we know it can be particularly difficult for children with ABI, who often respond best to set routines, structure and predictability.

Transitions may involve changes in physical location, activities, or social situations:

- Going from hospital to home
- Going back to school
- Returning to sport
- Moving from year level to year level
- Moving school to post-school options

Transitions can also involve changes in routine and support such as:

- A friend leaving school
- Mum having a new baby

Regardless of the type of transition, the advice from everyone is the same -PLAN for the transition and PREPARE your child for the transition as much as you can! One resource that may assist is the 'Who's Who?' form on the following page. This provides a way for you to keep track of all the people involved with the child each year. You can modify the form if/when changes in staff involvement takes place. You can also call on these people to assist you with planning and preparing transitions.

For further information on how to plan and prepare for transition or for forms that might help you to support your child, see the *Study Skills* Fact Pack.

For transition from primary to high school, see the *Choosing a High School* Fact Pack.

Who's who?

Sometimes when a child has an ABI, there can be lots of people involved. This is a useful form to keep track of them all. If your child has a rehabilitation coordinator, make them responsible for this one!

Name	Role	Contact details
School		
	(e.g. classroom teacher; learning support teacher; teacher aide;	Phone:
	etc.)	Email:
		Address:
		Phone:
		Email:
		Address:
Therapists		
	(e.g. Rehabilitation Coordinator; Speech Pathologist;	Phone:
	Occupational Therapist; etc.)	Email:
		Address:
		Phone:
		Email:
		Address:
Medical		
	(e.g. paediatrician; GP; etc.)	Phone:
		Email:
		Address:
		Phone:
		Email:
		Address:
Other useful contacts	s/resources	
e.g. Raising children network	Australian parenting website	http://raisingchildren.net.au

Return to school

For children with ABI, returning to school is a vital part of the rehabilitation process and needs to take place over a gradual period of time.

A smooth successful school reintegration is dependent on:

- Planning and preparation
- Communication between all the people involved, including your child's rehabilitation team, hospital staff and most importantly your child's school teachers and other staff.

Why is contact with my child's school so important?

Many children make a good physical however, problems recovery; attention, memory and learning may not become obvious until your child returns to school. Sometimes children who have had a head injury find it harder to concentrate in the classroom, remember new information, and may have a return or worsening of symptoms such as headache or nausea. Many experience fatigue and become tired much quicker than before. It is therefore important that teachers are informed if special educational help is needed, to achieve the best results for your child. For some children, they may only need a tutor or someone to help them organise their studying arrangements.

If your child has any physical requirements, it is good to work these

out before they return to school. For example, there may be a need for ramps where classrooms have steps, or some rearrangement of classroom furniture. This can be carried out by the appropriate rehabilitation therapists helping your child. They will be able to speak with teachers and principals to negotiate your child's requirements.

A meeting is usually arranged with teachers and any appropriate rehabilitation staff at the school before your child returns. This is a chance for the teachers to understand how your child's injury has affected them and what they can do to help. Your rehabilitation team will be able to help you talk to the teachers and organise strategies and techniques that will best integrate your child back into the school environment.

How will my child go fitting back into the classroom?

The return of your child to school will undoubtedly raise a mixture of feelings, such as excitement, apprehension, anticipation and most likely nervousness.

They may have some difficulty getting used to being back in the classroom with all its activity and distractions, as well as meeting up with friends and fitting back into their peer group. These difficulties may arise not only because of the changes your child has had since the brain injury, but also because of their absence from the classroom and the playground.

To help make your child and their classmates feel more comfortable, it can be useful to organise a time for your child's rehabilitation team or teacher to talk with your child's classmates, so they can understand what has happened and

some of the effects an injury such as this can have on their classmate. Many children enjoy helping other students with their class work and involving them in games at recess when they understand what has happened.

How soon should my child return to school?

An early return to learning in the school environment is an important part of rehabilitation. The return to school should be gradual to increase both mental and physical stamina. Some children may start back at school on a part-time basis, gradually building up their attendance time. In high school, this may mean attending at different times of the day as subjects are rarely time-tabled at the same time each day. As your child learns to cope with the physical and mental demands of school, a gradual return to full time attendance is usually possible.

What other assistance is available to my child at school?

In NSW, the Department of Education may make some provision for support for children following a brain injury. The level of support will vary depending on each child's problems. Support is greatest during the initial return to school and then may be reduced according to your child's needs. The support may include extra help in the classroom (teacher's aide), specialised equipment such as computers or note takers, and exam provisions during the high school years (e.g. more time to complete exams).

Wherever possible, children return to their own school. If your child needs a lot of extra assistance, a support class or a special school may be recommended. Some mainstream schools offer smaller classes for children with special needs in particular areas.

A Learning Support Team will most likely be established to help you determine the best options for your child and to ensure their learning needs will be addressed.

The LST will typically comprise:

- Team Facilitator (usually the Learning Support Coordinator / Teacher, or Principal)
- School Counsellor (who may also act as the Team Facilitator)
- Teacher representatives (e.g. Year Level Coordinator; Head of House; Senior School Coordinator, Home Room Teacher, etc.).
- Specialist Personnel (e.g. Reading Recovery, ABI workers).

They will meet regularly to coordinate, implement, monitor and evaluate your child's educational program.

Further information about LSTs is provided in the *Choosing a High School* Fact Pack. Other "Useful References" are listed at the end of this booklet.

Return to sport

Concussion: when in doubt, sit it out!

A concussion is a brain injury. It is caused by sudden strong movement of the brain against the skull due to a collision with another person or object. Concussion can happen in any sport or during play. Most concussion injuries do not involve any loss of consciousness (i.e., a child does not have to be knocked out to have concussion).

Common signs and symptoms of concussion include:

- Confused or dazed
- Memory loss
- Headache or 'pressure' in the head
- Nausea/vomiting or stomach ache
- Dizziness and/or loss of balance
- Feeling tired or drowsy
- Blurry or double vision
- Sensitivity to light and/or noise
- Feeling more sad / emotional / nervous

If a child receives a blow to the head or body that causes a jarring of the head or neck, check for signs and symptoms of concussion. If concussion is suspected, the child should be **removed from play immediately** and should not return until seen and cleared by a doctor. Most people fully recover from concussion, however the rate of recovery can be variable and differ across individuals.

Following a concussion, there should be a gradual return to activity before full participation in a sport or other physical activity. According to the Parachute Concussion Guidelines for Parents and Caregivers (2014), the signs and symptoms of a concussion often last between 7-10 days, but can also last much longer. The key to initial management of concussion is physical and cognitive rest in order to allow the symptoms of concussion to resolve. Your child should not exercise. use computer screens, play video games, or study for at least 24 hours. It is likely they will need some time away from school and sports. Once your child's symptoms have completely resolved at rest, they can start a stepwise increase in sport and activities. You should consult with your local doctor or health care professional before any return to activity.

A return to activity guideline developed in conjunction with the Sydney Children's Hospital Network which suggests a staged approach to safely return to sport and activity, is reproduced on the following page.

Even though it can be very hard for an active child to rest, and they may be keen to return as soon as they feel better, it is important to follow the graded approach to return to activity. Following a concussion, your child's reaction times and thinking can be slower, which can put them at risk of further injury. In addition, multiple concussions, particularly within a short space of time, can have a compounding effect, resulting in the risk of more significant, longer-term damage.

Information sourced from:

Ontario Neurotrauma Foundation. (2014). Guidelines for Diagnosing and Managing Pediatric Concussion.

http://onf.org/documents/guidelines-diagnosing-and-managing-pediatric-concussion.

Parachute Canada. (2014). *Parachute Concussion Guidelines for Parents and Caregivers.* www.parachutecanada.org

Sydney Children's Hospital Network. (2016). Kids' Health – Concussion.

https://kidshealth.schn.health.nsw.gov.au/concussion

RETURN TO ACTIVITY GUIDELINES FOLLOWING CONCUSSION				
Stage	Physical activity	Physical activity recommended	Recommended activities	Goal(s)
1	No physical activity allowed when there are any symptoms of concussion	No sports allowed	 Quiet time with rest Avoid groups, videos, reading, computers, video games, mobile phones and noisy places 	 Brain rest and healing (it can take days or even weeks for the brain to heal) Be symptom free
			s after doing Stage 1 activitions after doing Stage 1 activitions after the fore the forest and the forest after the forest and the forest after the forest and the forest after the forest after the forest and the forest after the forest and the forest after the forest afte	
2	Light activity	10-15 minutes of walking, swimming or cycling on an exercise bike – preferably daily. No weightlifting.	 Quiet play alone or with parent Avoid group activities 	Increase heart rate
		nysical activity again. If	Stage 1 and wait until the clean child remains symptom-frees, move onto Stage 3.	
3	Sport-specific exercise	20-30 minutes of running, cycling or ball skills. No weightlifting and no activities that would allow head or body contact.	Supervised playEasy activities	 Increase heart rate Add movement Use eyes to track objects
		nysical activity again. If	Stage 2 and wait until the clean child remains symptom-frees, move onto Stage 4.	
4	Non-contract training drills	40-60 minutes of more difficult training drills. May start weightlifting	Supervised playFitness training but no gamesMay run/jump as able	 Increase heart rate Increase resistance Sport or play without danger of head injury
		nysical activity again. If	Stage 3 and wait until the clock child remains symptom-frees, move onto Stage 5.	
5	Full contact practice following clearance from a doctor	After a doctor gives the OK, back to full practice sessions	Normal activities with supervision	 Build confidence Regain endurance Have skills judged by coaching staff (or family)
		nysical activity again. If	Stage 4 and wait until the clean child remains symptom-frees, move onto Stage 6.	
6	Return to play	Normal game play	Normal playtime and activities	◆ No restrictions

Thinking about you: Words of wisdom

In 2002, a group of families from the south west of NSW got together to share their experiences of ABI. The parents involved had some things they thought would be helpful for other parents of a child with an ABI to know. Here is a summary of some of the things they wished they'd known about earlier on in their child's recovery.

Mothers: What they wish they'd known earlier!

About their child

- Accept the person with the ABI as they are now
- Let siblings be who they are and live their lives with choice
- Remember that not everything about your child is the ABI. Children still go through normal developmental stages.
- Realise that children do learn new skills
- Let the kids have dreams like other kids

About their child's needs

- Ask medical services to talk in layman's terms
- Seek clarification of things
- •Don't be afraid of other people's qualifications
- Keep asking questions and find out about all your choices
- •Remember that parents are the experts about their children
- •If you can't get satisfaction from one service keep going until you are satisfied
- •Go on your gut instincts
- Set realistic goals to achieve. Focus on what you think is possible.

About their own needs

- Have someone to talk to, to let off steam
- Don't underestimate your own strength
- Have belief and hope
- Keep part of yourself separate. Have time out on your own.
- Accept help
- Only worry about what is most important. Let go of some of the smaller worries.
- Surround yourself with people who empower you and let go of people who bring you down
- Work out whom you are going to take advice from and forget the others

Fathers: What they wish they'd known earlier!

About their child's and family's needs

- Be patient
- Be determined
- Don't always believe what the experts say
- · Paint the picture for your child
- If you have something to say, say it
- Ask questions all the time
- Get another opinion if you are not happy
- · Ask questions of teachers
- Be there for your partner and family
- Give each other space
- Talk through problems
- The first month is the toughest
- Be positive, the children can read the negative
- Use the social worker at the hospital

About their needs

- · Confide in a close friend
- You need to have holidays
- Use respite (if you can find it)
- Encourage your child to play noncontact sport or do other activities
- Find something to compete in
- Have an interest be involved in a club
- · Hang in there

Thinking about you: Grief and loss

Grieving in some form is a normal reaction to any form of loss (e.g. a break up of a relationship, a death or a brain injury). When a child has had an acquired brain injury, parents can experience feelings of considerable loss. These losses can be practical (home. relationship. financial security) symbolic (hopes and dreams).

Grieving after your child has had an ABI can be quite complex and take time. People can experience the pain of loss each time their child tries to do something that they were able to do before their injury and now find they can't. Grieving may occur at the "milestones" that your child now achieves differently.

Some of the emotions that people experience when they are grieving include anger, fear, depression, sadness, numbness, disappointment, despair, guilt, and frustration. Everyone deals with grief and loss in their own way. There is no specific recommended "treatment" that can cure feelings of grief and loss. Time is a very important factor.

It is essential to recognise loss, acknowledge it and mourn. The trick is to express what you are feeling openly and honestly, but in appropriate ways like talking to someone. Trying not to think about feelings or challenges in an attempt to avoid the feelings doesn't help in the long term.

Whilst it is important to talk through your experiences to help make sense of what has happened, spending all of your time thinking and talking about your child's

injuries and the past can cause you to become stuck. Recovery means feeling good when something good happens, feeling hopeful about the future, giving energy to everyday life, laughing and being happy to be alive and finding ways to be with others.

Some key points to remember:

- Grief is not an illness
- Grief is a unique process for each individual
- Grieving cannot be hurried
- ♦ There is no right or wrong way to grieve
- People have different feelings and beliefs
- The absence of an outward show of grief does not mean that the person is not grieving.

While you are grieving you need to feel safe and supported, express your feelings as you grieve, tell your story and have your experience acknowledged and your distress and pain validated. You also need to go on living in a meaningful way and move towards re-establishing your life.

People around you might ask how they can help. There will be lots of practical ways but you could also give them some of the following ideas. They can help by:

- Being supportive and non-judgemental
- Taking the time to listen and empathise
- Involving you in decision making
- Resisting the urge to problem-solve
- Allowing you to grieve in your own way, including tolerating silences, tears, unhappiness and individual reactions
- Not saying "I know how you feel"
- Not jumping to conclusions

You could even give family and friends this information to read!

If you are concerned and would like to talk to someone about grief please call your local regional support services, such as Carers NSW on 1800 242 636, the NSW Mental Health Access Line on 1800 011 511, or Lifeline on 13 11 14 for support and advice.

Thinking about you: Looking after yourself

Having a family member with an ABI can be very stressful. The cause of an injury can be particularly traumatic, especially if totally unexpected or if someone else is found to be at fault. Adjusting to family changes after a brain injury can take months to years.

During this period, people can feel a variety of things, for example they may feel down and depressed; lose confidence and feel worthless; have mood swings; worry a lot or feel hopeless about their future; think about suicide or harming themselves. People can be confused or even frightened by the intensity of their emotional reactions.

It is important to remember that these feelings are normal; most people go through difficult times after their child has had a brain injury. This does not mean that they are going crazy but that they are dealing with very challenging situations. It is also important to remember that most people get through the difficult times and that many people find that over time they adjust to their changes and find value in their lives.

If you are feeling overwhelmed, there are some things that might help. Here are some ideas that other people have found useful. You could:

- Play music
- Get involved in enjoyable activitie
- Do something fun
- Talk to other people
- ◆ Try to help other people
- Use relaxation
- Speak to a counsellor
- Go to a doctor to talk about medication
- Write things down
- Try to think more positively
- Set realistic goals and then start to work towards them
- Try to keep fit and active
- Concentrate on the things you may be able to control: don't dwell on problems that you can't
- Join a club or sporting team

If you are feeling extremely upset and feel that you might do something to harm yourself or others there are some things that might help:

- Don't use alcohol or other drugs (they are likely to make things worse)
- Talk to someone about how you feel
- See a doctor
- Contact regional support services, the state-wide NSW Mental Health Access Line on 1800 011 511 or Lifeline on 13 11 14 for support or advice

Helping siblings

Sibling relationships are complex and are often characterised by dynamics such as love, hate, jealousy, rivalry, loyalty, competition and companionship. These relationships can become even more complicated following an ABI.

How does ABI affect siblings?

As you know, when a child has a brain injury it affects everyone in the family. Everyone deals with these events in a different way, including siblings, and their reactions may change over time. It is important that sibling's feelings are heard and understood.

Some common reactions that tend to occur among siblings are:

- Feeling guilty about the injury or guilty if they complain about it
- Behaving like a younger child
- Feeling resentful
- Feeling angry
- Feeling worried about their sibling and also their parents
- Feeling neglected
- Feeling confused
- Wanting to blame someone or something for the injury
- Feeling embarrassed when talking to peers about their brother/sister
- Being afraid of what the brain injury means (they may not understand that they cannot catch it)

- Grieving this can include shock, grief, guilt, anger and depression
- Changes to their role in the family

Some siblings are happy when their brother or sister returns home because they feel things can return to normal, but often it can also be a confusing time. For example, they may notice that their brother or sister is acting a little differently to the way they used to. They might get tired and cranky a lot and need more rests. They might have had difficulty concentrating or take longer to do things than they used to. They might sometimes forget the words they wanted to say. It can be confusing when their brother or sister looks the same and does most things the same but some are different.

It is important to let your other children know that what they are feeling is completely normal. Your family has been through a difficult time. They don't need to feel ashamed or embarrassed about how they feel or the things they are thinking.

What can you do to help?

Information and education

Most siblings report that they want information about their brother or sister's brain injury. Provide siblings with as little or as much information as they want (we've created a *Siblings* Fact Pack with information that might be helpful). Make sure that this information is at a level that they can understand. Sometimes siblings may not want information or to talk to anyone in the beginning, but may want to later — be sure to let them know that even if they don't want to talk now, they can ask at any time.

Feelings

Encourage siblings to talk about their feelings. Let them know that while this may seem scary to do, lots of people find that it helps to get things off their chest. Let them know that they can choose who they talk to, it might be you, a friend, a teacher, a health professional.

You can sometimes encourage children to share their feelings by talking about your own feelings. When children do talk about their feelings it is important that you are non-judgmental and let them know that their feelings are common. Give permission to feel upset, worried, concerned and angry.

If they don't want to talk you could suggest that they write down their feelings in a letter, diary or journal.

Siblings may find that counselling is a helpful way to share their story, talk about their feelings and learn new ways of coping. Counsellors are available through most schools or you could talk to your ABI worker.

Help your other children to work out ways to explain their brother or sister's brain injury to their friends. Help them to think of something simple but truthful to say to their friends. Also help them think of how to cope in situations if their brother/sister is teased. e.g. "Everyone has some problems but he is really good at ..." Bullying is not okay. It may be helpful to prepare your sibling in case it occurs.

Time out

Siblings need their own time. Encourage them to be involved in hobbies, sports and interests. Let them know that they do not always have to include the child with an ABI- just as we do not have to do everything with our partners or children.

Regular time

Make regular time to spend with the sibling. This could include time to talk about their interests, activities or school. You might have to get some respite care for the child with a brain injury so you can do something special with the sibling.

If you have planned to attend a special event, like a school or sporting activity, make a plan in case something goes wrong and you can't make it - a "just-incase" plan. Maybe there could be a back-up person who is nominated to go so it isn't missed or there could be an alternative special outing.

Responsibility

Children need time to be children. Try not to give them too many extra responsibilities on top of what is normal for their age. Many children will put on a brave face even in the face of difficulties and sacrifices. It is important to check in with them about how they are going. Be sure to thank them for their contributions and to acknowledge their achievements.

Openness and honesty

Give the sibling permission to ask questions and give them honest answers. Children worry too. If they want to know when their brother or sister will be better, be honest. If you don't know, say that. Let them know that while their brother/sister is likely to get better, recovery takes a long time.

Challenging behaviour

Siblings may "act out" as a result of changes in the family. Watch out for this and address issues like anger, resentment, jealousy etc. in an open and non-judgmental manner. Refer to the *Behaviour* Fact Pack for further information about managing challenging behaviour.

Involve them in rehabilitation

Some siblings want to get involved by helping the child with the ABI. Siblings should be given the opportunity to be included in their brother/sisters rehabilitation. However, remember that not all siblings will always want to be involved.

Link them with other siblings

Link them with other siblings who have a brother/sister with a brain injury. This may be difficult in small rural areas, however, there are some websites that may be useful including:

- Siblings Australia: www.siblingsaustralia.org.au
- Sibs (a UK-based charity): <u>www.sibs.org.uk</u>
- Child & Youth Health (South Australia Health): www.cyh.com
- Association for Children with a Disability (based in Victoria): www.acd.org.au/siblings/indexb. htm
- Livewire (powered by Starlight): www.livewire.org.au
- Side by Side Sibling Support Booklet (2011) available from www.adhc.nsw.gov.au

Talking with your child

Is talking with your child ever like getting blood from a stone? Have you ever asked "How was school today?" and just got "GOOD"? Have you ever listened to your child talking with friends or relatives and realised that they don't really know how to maintain a conversation? Have you ever thought that their description of events was wildly inaccurate or "all over the place?"

We know that our conversational style can make a huge difference to our children's cognitive and verbal development. Researchers tell us that parents use a number of "interactional styles." They have found that talking with a child in a friendly and fun way is more helpful than a style which is like a cross-examination.

We've also learnt that that talking about events, plans and activities with your child helps them to organise their thoughts and recall situations. Reviewing past events with your child and discussing plans has great value for them.

So what does this mean for us as parents? How can we talk with our children in ways that help them? We naturally communicate with friends in a way that is encouraging and fun. We need to apply some of these strategies in the way we talk to our children. For some of us this will be easier than for others, but we can all improve!

This section provides some ideas about how to communicate with your child in a way that is encouraging. There are also some hints from parents and therapists about how to use communication opportunities well and how to broach those tricky, sensitive topics!

Parental conversational styles: Talking with or talking at?

Rather than talking at your child, you want to talk with your child. What is the difference you ask? Talking at your child will discourage communication and shut down the conversation. In contrast, talking with your child will keep the conversation going and you will be encouraging communication, which is more likely to help them develop.

On the following pages are some examples contrasting the difference between talking with and talking at your child, which have been taken from Collaborative brain injury intervention: Positive everyday routines (written by Ylvisaker and Feeney, 1998).

If you are talking <u>with</u> your child you will	If you are talking <u>at</u> your child you will
Introduce a topic of interest that can be expanded and is interesting to the child. This will have the potential for elaboration.	Introduce a topic that the child isn't really interested in and that doesn't offer much to say
e.g. "You made a fantastic model here. How did you start?"	e.g. "So, what do you think about the global financial crisis and what effect will this have on the Middle East, if any?"
Maintain and continue a conversation topic for many turns and follow the child's lead.	Give non-specific responses or change the topic without giving the link
e.g. "And what did you need?"	e.g. "I'm going to watch TV."
"Oh, so you're building a castle! It looks fantastic! What's this part for?	
Contribute many pieces of information per topic, add information.	As above
e.g. "Oh right, like the ones we got at Spotlight?"	
"Windy, and I think it was blowing a gale!"	
Repeat information	As above
e.g. "Yeah, we didn't pick the best day, you can say that again."	
Express interest	Finish the conversation because you already know the story
e.g. "I had forgotten how funny that day was. This is good to remember it again!"	e.g. "Yes, yes, I was there. I remember
was. This is good to remember it again:	what happened. I know. "
Affirm contributions e.g. "That's right, it was blowing a gale."	Be pedantic or picky and criticise the child's response
e.g. That's right, it was blowing a gale.	e.g. "Oh, I hardly think it was a 'gale'. When I looked at the BOM website, it didn't predict gale force winds."
Invite more information	Not build on the conversation
e.g. "I wonder what happened when?"	
Ask open-ended questions that require more than a 'yes' or 'no'.	Ask closed questions e.g. "Was it raining?"
e.g. "What time of the year was that picnic? Vs Did we go on that picnic in Winter?"	"Do you like to build castles?"

If you are talking <u>with</u> your child you will	If you are talking <u>at</u> your child you will
 Try to organise information: ◆ to provide a sequence e.g. "Oh, so first you, then you" ◆ explain causes and effects e.g. "I think it probably broke when you dropped it!" ◆ include emotional reactions e.g. "You cried because you were scared, lots of people do that!" ◆ explain similarities and differences e.g. "Just like when we" ◆ extend conversation by introducing an analogy/association e.g. "That reminds ofbecause" 	Not use correct sequence or help child order information logically. Stuff like: "Oh, really" (meaning "I am not interested!") "Uh-huh" (meaning "Come back after the TV's off!")
Review organisation of information and the whole topic e.g. "So when you" e.g. "So we were on the picnic in the freezing cold, wanting to be home, and then, can you believe it?!" e.g. "I'm trying to remember the day from when we began in the morning to getting home, can you help me?"	Not review information in the topic of conversation
Correct in a non-threatening way e.g. "Did we run to the car or was there that funny old shelter?" Address problems and solutions e.g. "How could we do this better next time?"	Correct in an authoritative manner e.g. "We didn't run to the car. We ran to the shelter. You're wrong." Criticise your child e.g. "You got that all wrong!"
Share information, not just demand it e.g. "I had a good day today. How was yours?" vs "Tell dad what you did today."	Demand information e.g. "Now, I've got a notes from Mrs. Jones here. Who visited your sports day?"
Respect your child's concerns	Not respect child's concerns or have your own agenda
Plainly acknowledge the difficulty of the task e.g. It's hard to put all these things in order isn't it?	Not acknowledge the difficulty of the task

If you are talking <u>with</u> your child you will	If you are talking <u>at</u> your child you will
Uses specific questions that include cues e.g. "Did we go swimming next?"	Ask non-specific questions without cues e.g. "What happened next?"
Give emotional support and respect your child's concerns e.g. "You look like you're too upset to talk about this now. Let's make a note in the communication book to talk about it later."	Not give emotional support or respect your child's concerns, and your own agenda e.g. "Pull yourself together! What form was it?"

Getting the most out of talking with your child

There are a number of things that will encourage better communication between you and your child! Some ways to ensure "good" conversations include:

Timing is important

Be aware of fatigue! The end of the day isn't always the best time for a heavy conversation.

Make some time available where your child has your undivided attention (e.g. walking the dog, going out for a milkshake or having a cuddle in bed in the morning).

Work on a fun project

Work together on making something (e.g. cooking, gardening, making a model). This is a shared experience that can provide a topic of conversation in the future.

Write a letter, record a tape or make a video for someone your child hasn't seen for a while. Help them plan what they will write/say and how they want to do it (i.e. interview format versus something less structured and formal). Make a script and most of all make it fun! Making a video also gives your child an opportunity to look at what he is doing right and wrong!

Consider different points of view

Encourage your child to have different opinions to you or their friends (without fighting!) and encourage discussion about the different ways to look at and approach the same idea.

Pay attention to your own talking

Be aware of your child's level of understanding. You may need to speak more simply or use shorter sentences. You may also need to speak more slowly to help your child understand what you are saying.

Use repetition & extra cues

You may need to repeat instructions and directions. Use gestures or pictures to help your child understand.

Explain new concepts & vocabulary

We know that new learning is difficult for children with ABI, so only introduce a small number of new words at a time. New words should be used over and over again in a variety of settings until your child masters the word and its concept.

Monitor your selection of words, expressions and comments

Some kids with ABI have difficulty understanding sayings, puns and idioms (e.g. "I have a frog in my throat," or "It's raining cats and dogs") and humour. Sarcasm is also difficult to grasp. It may be necessary to explain the meaning if this abstract language is used. It is also best to avoid this type of language when it is crucial that your child understands the information being given to them.

Organise & sequence information

Children with ABI can have difficulty with informal conversations because they sometimes lack organisational skills. Look out for signals that your child is confused by the conversation and be ready to step in and use words like 'first', 'next' etc. This will also help your child learn to structure conversations.

Announce and clarify the topic of conversation

For example when preparing to change subjects say, "Now let's talk about Finding Nemo."

Allow adequate response time

To help kids understand conversations you may need to wait a little longer for children to process what they have just heard and generate a response.

Teach your child to be aware of others' responses

Children with ABI are often unaware of others' reactions and so breakdowns in communication often occur. Teach your child to watch other people and identify facial expressions that may signal confusion, loss of interest etc. This can be done using photographs of different facial expressions and training what these mean.

You will then need to teach your child some ways of dealing with this so the communication doesn't breakdown. This can include role playing different situations and making a plan for what to do when someone looks angry/ happy/sad etc.

Arrange the physical environment

Children with ABI often don't cope with distractions or competing demands. If your child is having trouble participating in a conversation, reduce distractions – turn off the TV or radio, move to a quiet corner, face the child away from windows, arrange chairs and table so you are facing each other, stop what you are doing and give your child your attention.

Taken from *Children with traumatic* brain injury: A parent's guide (edited by Lisa Schoenbrodt, 2001).

Games that encourage talking

There are many games where you and your child can practise good communication skills. If your child is working with a speech pathologist, they may have lots of suggestions. Some commercially available games that we think are good include:

- ♦ Guess Who?
- ♦ Articulate
- ♦ Mix-Max
- Junior Trivial Pursuit
- Scattergories

Then there are the "car" games:

- ◆ "I Spy"
- ◆ "Animal, vegetable, mineral"

(Someone thinks of an object that falls under one of the three categories. Players then take turns asking questions that can be answered with Yes or No)

- "I went to the shop and I bought..." (The first player starts by saying the above phrase and stating one item they bought. Subsequent players need to state a new item as well as recall all the previous items that each player bought in order)
- Go through the alphabet and take turns to list all the fruits/vegetables, singers, foods etc. that start with each letter

- "Charades" (act out a word or phrase without speaking while others try to guess what the phrase is)
- "Twenty questions" (ask up to 20 yes/no questions to find out another players chosen word/object)
- "Word associations" (The first player starts by saying a word, then the next player says a word off the top of their head that is connected to the previous word)

There are also an increasing number and range of smartphone/tablet Apps that can be used to encourage talking. Some free ones include:

♦ Heads Up!

A game of charades with a category just for kids.

- ◆ SparkleFish An audio story completion game.
- ◆ Guess the Person? HD Free An app version of Guess Who.

Communication - More than just 'talking'

Thinking about your child's communication means you are not just thinking about what they say but how they say it! Your child may be talking to you about lots of things but it still doesn't come out right. Below is a checklist of questions you can ask about how your child is talking. The answers may help you identify areas in which your child needs feedback and guidance to communicate better. The questions may be useful information if your child is working with a speech pathologist.

Body language and manner

- Is your child making eye contact?
 Is the eye contact inconsistent or inappropriate?
 Is gesture being used appropriately?
 Does your child have false starts or lots of hesitations?
 Does your child have lots of repetitions, unusual pauses etc.?
 Does your child have a long delay
- ☐ Does your child take into account the listener?
- ☐ Does your child take turns in a conversation?
- Does your child listen well?

before responding?

Amount of information

- ☐ Does your child provide enough information?
- ☐ Does your child use a lot of nonspecific vocabulary? e.g. words like thing, stuff, this, there etc.
- ☐ Does your child give too much or more information than is needed?
- ☐ Does your child get stuck on topics?
- □ Is the information accurate?

Conversation skills

- ☐ Can your child maintain a topic in a conversation?
- ☐ Does your child respond inappropriately?
- ☐ Does your child ask appropriate or needed questions?
- ☐ Is your child's language style right for the situation? (e.g. not too formal?)
- ☐ Are your child's comments and questions well-timed?

Your child may be working with a therapist or teacher on some of these skills. You can help at home too. For example, you could say, "You need to look at Grandma when you are talking to her. Then she knows to listen" or "You have already told me what a brontosaurus looks like. Tell me something different now. What did he eat?" Usually, we just "know" how to join a conversation and stay involved in it. We "pick up" what people mean language bodv or facial expressions. Your child may have to learn these skills.

Here are some activities that you can do together as a family that may help develop child better your communication skills. They have been taken from a book called Semantic -Pragmatic Language Disorder (written by Charlotte Firth and Katherine Venkatesh, 1999). For more ideas ask a speech pathologist at your ABI team or local Community Health Centre.

- With your child, think up phrases that usually start, continue or finish a conversation (e.g. "Hello, how are you?" or "Oh, by the way"). Does your child know where they might occur in a conversation and why?
- Watch a TV program with your child and write down the conversational "starters", "continuers" or "finishers" that are used.
- Take turns with your child to act out different scenarios like "opening a present" or "feeling sick." Each try to guess what the other is doing. You can sometimes try to do this activity without words to encourage the interpretation and expression of non-verbal language.

- Write different emotions on pieces of card and take it in turns to act out the emotion shown either with body language, facial expression or tone of voice.
- ◆ Have family "news" time where you all practise taking turns, staying on a topic and where you have a "quiz" at the end. For example, "Who went to the doctor's today?"
- Make a family "Things to remember when talking" chart and put it where it can be easily seen. Based on this be specific with both your praise and your correction. Always explain both why and how your child should stick to the rules e.g. "Oh dear, you talked too fast so I couldn't understand you" or "Great, you waited your turn so we could all say what we wanted to."
- Your child may benefit from joining a drama group or children's theatre if there is one in your town.

Broaching the 'tricky' topics

Now that you've practised talking with your child and you have lots of ways to communicate with them in an encouraging manner, let's get onto the tricky topics! As your child becomes a 'teenager', you may need to start talking about other sensitive issues. How do you know when the time is right?

As with any conversation, it's best to gauge how your child is feeling. If they are fatigued or have a headache, it is better to wait for a time when they feel more 'fresh'. It's also a good idea to reduce distractions to get the most out of these important discussions.

Things like school events and learning material, movies, TV shows, music, social media, and news stories can prompt meaningful conversations about important topics.

The following is not 'must do' list and we don't suggest you sit down and tackle all of these topics in one conversation! They are simply some 'good tips', 'good questions' or 'smart comments' to use when broaching D&M (deep and meaningful) topics with your son or daughter.

The following information is based on the article *Getting into adolescent heads: An essential update* (by John Goldenring & David Rosen, 2004), the work of the Centre for Adolescent Health and Welfare in Melbourne, and the experience of the staff on the Kids' Team.

Let the young person teach YOU something, let them know something you don't

- Can you explain Facebook / Twitter / Bluetooth to me? I don't get it.
- Can you show me how to upload photos from my phone onto the computer?

Grief and loss

- You must never have thought you'd end up here in your life...
- What's something you miss since your injury that no one would realise?

Feelings

- Some young people feel really angry, like they could smash something to pieces, because of what's happened to them...do you ever feel like that?
- Sometimes people feel really sad or worried a lot of the time, and they don't always know why...has that ever happened to you?

Start less intrusive and then more personal

- Have any of your friends tried alcohol or cigarettes? Have you ever tried them?
- Do you know anyone your age who has had sex? What did they say about it? Have you ever thought about it?

Exaggerate a bit so they feel comfortable to tell you their experience

- So I guess you'd be drinking every Friday, Saturday and Sunday nights when you're at Mark's place? No way! Only Friday and Saturdays Mum! Not on a school night.
- You must be smoking a pack a day...Nah only every three days.

School

- What do you like about school? What are you good at, not so good at?
- Many young people experience bullying at school, have you ever had to put up with this?

Eating and exercising

- Are you happy about your weight?
- Tell me what you think about your weight and shape?
- Tell me what you like / don't like about your body?

Drugs

- Do you ever feel pressured to try things like ecstasy or ice?
- Many young people at your age are starting to experiment with cigarettes or alcohol...have your friends? Have you?
- What effects does drug-taking or smoking or alcohol have on your friends, do they change?

Sexuality

 I know this is a bit embarrassing but...some young people your age are getting involved in sexual relationships. Have you had a

- sexual experience with a guy, a girl, or both?
- Sometimes when people realise they are attracted to people of the same sex, they can find that really hard to deal with. Has that ever happened to you or anyone you know?
- Has anyone ever touched you in a way that has made you feel uncomfortable or forced you to do something you didn't want to do?
- How do you feel about relationships in general?

(You might not get answers the first time you ask, but by asking you're letting them know it's safe to talk to you about these things.)

Suicide and mood

- How do you feel in yourself at the moment on a scale of 1 to 10?
- Some people who feel really down often feel like hurting themselves or even killing themselves, have you ever felt this way? Have you ever tried to hurt yourself?
- What sorts of things do you do if you are feeling sad / angry or hurt?
- Is there anyone you talk to about this kind of stuff?

Safety

- Sometimes when young people are drunk or high, they do not think about what they are doing. Have you ever driven a car when you were drunk or high?
- Have you ever ridden in a car with a driver who was drunk or high?
- Have you ever felt that you needed to carry a knife or weapon to protect yourself?

Summing up

- If you had to sum up your life in one word, what would it be?
- What's the weather report for you today (e.g. pretty sunny with a few clouds = happy with a few assignments due!).
- What do you see when you look in the mirror?

The research suggests that young people want to talk about these sorts of issues, but they will not offer the information unless they are asked. Pick the right mood, the right time and the right space... and see how you go! If you would like to discuss this more, please feel free to talk to your contact person from The Kids' Team, your GP or other health professional.

Helping your child to study

There are a number of different study techniques that can help children learn and remember information. Some of these techniques are included here. Encourage children to try different techniques and work out which ones are better for them. We all learn in different ways and we need to find out what way is best for us. For examples of forms to use when trying out these ideas, see the *Study Skills* Fact Pack.

Taking notes

Taking notes during class can be difficult for your child. It's hard to remember what to write, write it quickly, and keep listening to a teacher – talk about doing lots of things at once! BUT...there are ways to make this process easier!

Taking notes from what he's reading is another challenge for your child. Making notes from information on the internet is often even more difficult than taking notes from books. There is often so much information and it is harder to find the main points. Some parents find the internet useful for maps and pictures but use books for written information.

The following strategies can be used either in class or when your child is reading.

Audio-record the class

Audio-record the classes that usually have lots to write (e.g. English and History). Your child can take notes during the class, and if they miss anything important, they can always listen to the recording again.

This method would work best if your child listened to the recording and added more notes during "homework time" (i.e. after school) the same day. That way it's still fresh in your child's mind, AND he is reviewing the work, helping it to stick better in his brain!

Use teacher handouts

If the teacher gives out handouts (or even if they don't – you could always ask them to!) then this method of note taking can be very effective. While the teacher is talking, your child can add his notes to the main points already on the handout.

For some children, the most helpful thing will be to ask teachers for a copy of notes in advance. This means he will be doing just one activity, listening. He is not trying to listen AND decide what is important, remembering it long enough to write it down and thinking about what that means. Your child can hear the information and then use the notes for review later.

Organising assignments

For your child this may be the most challenging part of learning to learn. When your child has difficulty starting a task, it is often because he does not know how to get started. In this section, we will suggest some tools that may help your child to organise his thoughts so he can know how to start!

Whether your child is doing the same assignment as the rest of the class or whether he has modified assignment work, he still needs to know how to plan and organise an assignment. If your child is finding an assignment too hard, talk about simplifying it with the teacher. Some teachers are happy to change the amount of work required. Others may alter the questions being asked. Some teachers may provide more time and structure for your child.

Most children think that we are organised because we are adults and we have to be. We need to make our own organisation obvious to children and include them in the "behind-thescenes" planning. For example, talk about what you are doing and how you plan to do it.

Encourage your child to ask key questions:

- What is my problem?
- ♦ How can I do this?
- ♦ Am I using my plan?
- ♦ How did I do?

There is a lot more information on this in the *Study Skills* and *Achieving Goals*Fact Packs, including a detailed description of the Goal-Plan-Predict-Do-Review (GPPDR) routine for goal setting.

Helping your child sleep

Getting children to bed and having them stay there can be one of the most aspects of parenting. challenging Children with an ABI are no different to other children in this regard. People often seek help with this problem because it can really affect everyone's wellbeing. At the end of the day we're all likely to be a bit stressed and tired, and not at our best. Most parents are looking forward to some down time alone or together and the chance to relax. Children may pick up on this and resent it, or they may get the idea that fun is about to happen and they are going to miss out on it! They can be really overtired and irritable, which makes them harder handle, to especially if they begin struggling to postpone bedtime, or get up again once they are there, or keep calling their parents back to tend to them. exhausting!

Following are some suggestions for sleeping, much of which has been reproduced from an article entitled **Bedtime** without struggling (by Kathryn Kvols and Helen Hall, 2013):

Respect your own needs. Don't overburden yourself in the daytime to the point where you are desperate and frazzled at your child's bedtime. Set your child's bedtime at an hour which allows you to enjoy some time for yourself, or for you to connect with your partner.

- Have a consistent bedtime every night. Even if your child does not go to sleep at this time they should be in bed at this time.
- ◆ Adjust your child's bedtime as he gets older. If your child is unable to fall asleep for a long time several nights in a row it may be time to have him go to bed later. Older siblings should go to bed later than younger ones even only ten minutes to feel important, and have the chance for one-on-one time with parents.
- It really helps to have both parents take part in the bedtime ritual if possible. It's more fun, and less of a burden if you share the process.
- Start the bedtime ritual about an hour before the actual bedtime, and work through a regular, predictable routine (e.g. dinner, bath, quiet play, brush teeth, bedtime story, kisses and a song or prayer). Keep the atmosphere as calm as possible so it is easier for your child to wind down. It is not the time for wrestling with dad, cliff-hanger stories or lots of tickling and giggling. Rotating the same few bedtime stories feels reassuring and settling to your child. Poems and songs can have a lovely rhythmically soothing Meditation or relaxation at bedtime can also be helpful (see following section).
- Minimise screen time before bed. Devices such as TV, computers, mobile phones, and other electronic devices can distract from sleep and delay sleepiness. These electronics emit a 'blue light' which actually results in physiological effects on decreasing body by the production of melatonin hormone associated with sleep) and shifting our body's natural circadian rhythm. It is recommended these

- are turned off at least one hour before bedtime.
- Give your child friendly warnings that bedtime is approaching, "In ten minutes it will be time to brush your teeth and hop into bed for your story"
- Offer choices rather than issuing commands, "You can go to bed now and have two stories or play with your Lego for a bit longer and have only one story." This will give your child a greater feeling of control over what is happening, and is helpful with a child who wants more independence, "Do you want daddy to bath you or mummy?" or "Would you like to sleep with Teddy or with Humpty?"
- Think about your child's sensory experiences: are their pyjamas or blankets itchy? Do the fabrics breathe? Is the room too warm or too cool? Do the blinds let in too much light? Are there smells coming from the kitchen? Everyone has different preferences: recognise your child's and help them feel comfortable for bedtime.
- Keep the TV off until your children are asleep. Half-heard shows can be distracting at least, and at worst can trigger anxieties. Lying in bed, children can remember or imagine scary scenes that upset them and make them want you near.
- Recognise that falling asleep can be difficult transition for some children. Going to bed means being alone and separating from parents. They want to delay this so they come up with every tactic they can, to including trips the toilet, desperate thirstiness, or anything that will work! They may even bring up a new concern to manipulate you into talking longer with them. You could try reassuring them in a

- friendly voice, "I understand you feel worried about that. I'd be happy to talk about it with you tomorrow. Right now it's bedtime."
- Allow a wakeful child to keep the light on and read quietly in bed. If they stay up late for a few nights in a row at first, don't worry, they will crave an earlier bedtime soon enough. They are starting to learn self-management skills.
- If a child keeps reappearing after being put to bed talk with them earlier in the day about what is acceptable. Do this when you are both calm and getting along well. Tell your child that if they get up after the bedtime routine complete for any reason that is not an emergency you will not talk to them. You will simply lead or carry them calmly back to bed. Follow through on this. especially remembering not to talk to them. If you begin to give reasons or answer them you will end up in a verbal power struggle. Smile, stay gentle in manner, and guide them back without delay. It may take a few times but your child will learn that you won't change your mind.
- Ponder the fact that it is often a parent's ambivalence about bedtime routines that allows a child to try to break the rules or rort the system. Be clear and concise about your bedtime rules. Don't allow the guilt of being a working parent, or your desire to interact more with your child erode your purpose and clarity. Just be determined to enjoy the time you do have, and then respect your child's and your own needs. Consider the benefits for your child that regular sleep and security will bring, and the benefit for yourself and your partner of having the routine in place, and then commit to making it happen!

Helping your child to relax

Relaxation refers to the process of producing a feeling of physical and emotional calmness by reducing electrical activity in the muscles of the body (Walker & Messer, 2003). Relaxation exercises interrupt the feedback loop that causes anxiety to spiral, and hence increase a person's ability to tolerate stress and tension by returning them to a calm, resting state.

When children are young, they are open to new ideas. However, being young can also be a time of worries and fears that are hard to express. Relaxation activities may help children to understand, express and overcome some of those fears and worries.

Relaxation and meditation can help children in a number of ways:

- Improve concentration
- Develop imagination and creativity
- Children can learn to relax and feel more controlled and calm
- It can help children go to sleep peacefully
- It is a way of bonding and sharing with their parent - a special time

Relaxation exercises are terrific for children of all ages and all abilities. You may find them very beneficial with your children without ABI!

During relaxation activities, speak with a very slow, relaxed voice, and allow frequent pauses to let the scene sink in. Drop your voice by a few tones, speaking more and more slowly, with a soothing quality.

The following section has some examples of things you can do with your child to aid in relaxation and reduce worry and anxiety.

The power of a positive mindset

For both children and adults alike, the way we think guides our feelings and behaviour. By listening to the language children use, we can help to make them aware of negative thought patterns, which can be contributing to Some common negative anxiety. includes thinking use the of exaggeration, extremes (e.g. always/never...), or speculation (e.g. 'what if...'). Work with your child to challenge the thoughts that are not based on fact or reason, and help them come up with more reasonable. self-affirming statements.

Mindfulness

In recent years, mindfulness has become an increasingly popular form of meditation, and is used in the treatment of a variety of areas, including stress, resilience, anxiety, and depression.

Engaging in beginner mindfulness is a straightforward strategy to help lower children's anxiety (www.parent.co). One way to do this is to practice gratitude: for example, both you and your child each sharing three things you are feeling thankful for at that moment. This helps draw your child's thoughts into the present moment, rather than worrying about the past or future.

One particularly good mindfulness resource we have come across is **Smiling Mind** – a modern meditation resource for young people which has been developed by psychologists and health professionals. It is available online www.smilingmind.com.au and can also be downloaded as a free smartphone App.

Smiling Mind includes a range of programs that have been adapted for children of all age groups (e.g. 7-9 years; 10-12 years; 13-15 years; 16-18 years). There's even a program for adults! All the programs are designed to assist people in dealing with the pressure and stress of everyday life, and can also help with issues such as relationship building, and communication skills.

Just breathe

Do not underestimate the power of a few good quality deep breaths! Sit/stand up straight, draw a nice deep breath in, hold and repeat — try counting to four during each inhale and exhale.

This has a positive physiological impact on an anxious body by lowering stress hormones and blood pressure, and promoting the delivery of oxygen to the brain, (i.e., helps to facilitate problem-solving).

Guided meditation

Guided meditation (visualisation) can be a great activity to use with your children. Please refer to the 'Useful References' list at the end of this booklet for a list of resources regarding guided meditation and relaxation. One book that many parents have found useful is **Starbright: meditations for young children** (written by Maureen Garth, 1991). Maureen starts each meditation with a focal point, in her case a star, which shines peacefully on the child. This sets up the conditions for meditation, it is the starting point for relaxation and visualisation. She follows this with a guardian angel, a worry tree and then the guided visualisation.

You can use your own words and own imagination to develop meditations. You could use the sun or moon instead of the star. You can make up your own meditations by speaking of your child's favourite toys or activities.

Body relaxation

Following a brain injury, some children may have difficulty with the technique of a guided relaxation. A body relaxation exercise may be more helpful for them as it relies on concrete rather than abstract processes.

A sample body relaxation exercise

The following section provides a childfriendly version of a body relaxation exercise, adapted from Relaxation Instruction **Training** (by ΤН Ollendick). You can use the following script with your child to introduce them to the idea of relaxation. You might want to do the whole thing, or just the preamble (Why do relaxation?) and one or two parts of the body. Over time, you will not need to read the script and eventually your child may be able to do this for himself or use an audio recording.

Why do relaxation?

We all feel tense and nervous sometimes. When this happens our muscles can get tense, we might feel sick in the stomach or get a headache. Some people get tense when they are meeting new people or get nervous when they are taking a test.

We can make ourselves feel better by learning how to relax. We are going to play a game where you will learn how to make your muscles relax. If any muscles are sore and tensing hurts, be sure to stop the child tensing those muscles.

Hands and arms

Pretend you have a tennis ball in your left hand. Now squeeze it hard. Can you feel the tightness in your arm and hand as you squeeze? Now drop the tennis ball. Notice how your muscles feel relaxed.

Now take another tennis ball and squeeze it hard. Squeeze it harder than the first one. Keep squeezing it harder. Now drop the ball and let your hand and arm relax. Good. See how much better they feel when they are relaxed. (Repeat process for the right hand and arm).

Arms and shoulders

Now I want you to pretend you are a big, furry, lazy dog. You have been sleeping all day and are having a stretch. Stretch your arms out in front of you. Raise them over your head. Way back over your head. Feel the pull in your shoulder. Keep stretching them higher. Now let your arms drop back to your side.

Now lift your arms as if you are trying to cover your ears. Keep shrugging them up. Keep shrugging. Now relax.

Now furry dog, stretch your arms out in front of you. Pull them over your head. Back. Try to touch the ceiling. Stretc.h. Hold tight. Great. Let them

drop back quickly and feel how good it is to be relaxed.

Shoulders and neck

Now pretend you are a turtle. Imagine you are relaxing on a nice sunny rock. It feels nice to be relaxed. Now imagine you want to hide. Pull your head inside your shell. Pull your shoulders up to your ears. Hold in tight. Now let your shoulders relax.

Pull your head into your shell again. Pull your shoulders up to your ears. Push your head down into your shoulders. Hold it tight.

Okay, you can relax now. Notice how much better it feels to be relaxed than all tight.

Jaw and face

Now clench your teeth. Bite down hard. Let your neck muscles help you. Now relax. Just let your jaw drop.

Clench your teeth again. Bite down. Hard, hard as you can. Harder. Good. Now relax again. Just let your jaw drop off your face. Try to relax your whole body.

Now imagine you have just seen something really yuck. Screw up your nose. That's right, wrinkle up your nose. Good. Now you can relax your nose.

Now screw up your eyes. Screw them tight. You don't want them to open. Hold them tight. Great. Now relax. Let's try that again. Screw up your eyes again. Try to screw them really tight so your eyelashes touch your eyebrows. Hold it. Tight. Now relax. Let your face go smooth. No wrinkles anywhere.

We have almost finished with your face. Imagine a big koala has just jumped out in front of you. You are surprised. Make a face like surprised! Raise your eyebrows. Feel the wrinkles in your forehead. Hold it. Hold it really tight. Now relax. The koala has gone.

This time a big emu has jumped out in front of you. You are really surprised. Raise your eyebrows really high. Feel the wrinkles in your forehead. Hold it tight. Now relax. Let your face go smooth. Your face feels nice and smooth and relaxed.

Stomach

Well we have seen koalas and emus and next comes a baby kangaroo. He hasn't seen you lying on the ground. You don't have time to get out of the way. Oops, he is going to jump on you. Make your stomach muscles really tight. Push your stomach out to tighten it. Hold it tight. Tighter. He's jumped over you. Relax. Let your stomach go soft. Let it be as relaxed as you can.

Oh no, it is the kangaroo again. He is coming your way. Get ready. Tighten your stomach. Make it like a rock. Tighten it. Hold it. Okay, he's gone. Relax now. Let your stomach go. Relax. Notice how your stomach feels. That's how you want it to feel. Nice and loose and relaxed.

Legs and feet

Now pretend you are at the beach. You are standing in warm soft sand. Squish your toes down into the sand. Try to bury your feet into the sand by curling and squishing your toes. You'll probably need to use your legs

to help you. Push down. Squish your toes. Now relax. Relax your feet. Let your toes go loose. It feels good to be relaxed.

Let's have another go. Squish your toes into the warm sand. Push down. Spread your toes apart. Feel the sand squish up between your toes. Keep squishing and squeezing. Use your legs to push your feet into the sand.

Okay, stop. Relax your feet. Relax your toes. Relax your legs.

Let your whole body relax. No tension anywhere. It feels good to be relaxed. You feel warm and tingly. All relaxed.

Progressive muscle relaxation

Progressive muscle relaxation is one of the simplest techniques for learning to relax. It involves focusing on relaxing all the muscle groups one by one. It may be more suitable for older children and teenagers. A possible script has been reproduced below from the *Encyclopedia of Clinical Child & Pediatric Psychology* (edited by T.H. Ollendick & C.S. Schroeder, 2003).

Once the child is sitting in a comfortable chair or lying down on a couch or bed, have them say to themselves:

"I am going to relax completely. I will relax my forehead and scalp. I will let all the muscles of my forehead and scalp relax and become completely at rest. All of the wrinkles will smooth out of my forehead and that part of my body will relax completely.

Now I will relax the muscles of my face. I will just let them relax and go limp. There will be no tension in my jaw.

Next I will relax my neck muscles. Just let them become tranquil and allow all of the pressure to leave them. My neck muscles are relaxing completely.

Now I will relax the muscles of my shoulders. That relaxation will spread down my arms to the elbows, down the forearm to my wrist, hands, and fingers. My arms will just dangle from the frame of my body.

I will now relax the muscles of my chest. I will take a deep breath and relax, letting all of the tightness and tension leave. My breathing will now be normal and relaxed, and I will relax the muscles of my stomach. Now I will

relax all of the muscles up and down both sides of my spine and let that relaxation spread throughout my back.

Now I will relax the waist, buttocks, and thighs down to my knees. Now the relaxation will spread to the calves of my legs, ankles, feet, and toes.

I will just stay here and continue to let all of my muscles go completely limp. I will become completely relaxed from the top of my head to the tips of my toes".

If your child has trouble doing this exercise, or for younger children, they may benefit from being taught how to discriminate between tense and relaxed states. This can be done by getting your child to deliberately tense their muscles a few times and then let them relax completely following the forced tension.

Helping your child in a crisis

The following are tips taken from *Nitty* gritty parent guide to managing a behavioural crisis (written by Mark Ylvisaker, 1998).

These ideas are not a substitute for a behaviour management plan but may help you get out of a tight spot if a crisis occurs (you know - in the supermarket!). See the *Behaviour* Fact Pack for more information, or the *Achieving Goals* Fact Pack for some ideas on how to avoid getting to crisis point!

Crisis do's

- Do help your child to identify personal feelings
- Do remember to look as if you know what you are doing
- Do be certain that your behaviour clearly indicates that you are trying to help
- Do remember to look stone-faced
- Do remember that "this too shall pass"
- We often say "He really knew which buttons to press today." Do try to find your "buttons" and hide them

- Do ask yourself, "Is it really worth making an issue of this?"
- Do choose your battles wisely, "Is this an issue worth fighting over?"
- Do ensure that everybody is safe and defuse the crisis as quickly and efficiently as possible
- Do consider letting some things go rather than making a situation worse (e.g. avoid saying "I hope you learnt your lesson when...")

Crisis don'ts

- Don't plant the suggestion of problem behaviour
- Don't threaten consequences
- Don't present commands as questions or pleas
- Don't have more than one person speak at one time
- Don't restart a confrontation by demanding immediately that the person begin a difficult activity
- Don't rehash the incident in front of another person
- Don't confuse crisis management with behaviour management

Summary

A childhood brain injury does not just affect the child who sustains the injury, but has the potential to affect everyone in the child's family. This Fact Pack was developed to provide parents with information about how the family might be affected, and ways to minimise the negative impacts and maximise the rehabilitation process.

As parents, you will receive lots of information about brain injury. In this pack, we aimed to give you some specific and practical information that has been shared with us by families who have been through similar experiences, and the therapists who have worked with them. We hope that you can relate to their insights, be encouraged by their advice and use their strategies in the coming weeks and months.

Remember that recovery from a brain injury takes time and differs from one child (and family) to another. It is normal to grieve, and it is normal for you and your family to do this differently. It is also normal for you to need time to adjust to changes.

While assisting your child and family through the recovery process, it is also important to look after yourself (as well as your child with brain injury, and other family members). You will be the most effective parent if you are healthy and well. Access resources and use your support networks (people and community groups/organisations) to ensure your wellbeing is being looked after.

Suggested resources are listed on the following pages if you would like further information about content covered in this Fact Pack. However, you are also welcome to contact the Kids' Team (Ph: (02) 6041 9902 or email MLHD-Albury-SWBIRS@health.nsw.gov.au) or the therapist working with your child and family if you would like further help or support.

Useful references

GEBERAL WEBSITES

Association for children with a disability. www.acd.org.au

This is the site of an information, support and advocacy organisation for children with a disability and their families based in Victoria, Australia. It is largely run by parents of children with a disability and covers a variety of types of disability. It has some excellent resources about advocacy and sibling support.

Kidsmatter. http://www.kidsmatter.edu.au

An Australian initiative developed by mental health professionals and education and childcare staff to support mental health and well-being of children in early childhood and primary school.

Parent Co. www.parent.co/about/

A digital publication for parents.

Raising Children Network. http://raisingchildren.net.au/

The Australian parenting website that provides evidence-based content on hundreds of topics about raising children and looking after yourself as a parent. The information is not specific to children with ABI.

Royal Children's Hospital (Melbourne). www.rch.org.au

This is the website for the Children's Hospital in Melbourne. It has information, fact sheets and links to resources about ABI.

Smiling Mind. http://smilingmind.com.au/

A not-for-profit organisation that works to make mindfulness meditation accessible to all.

Sydney Children's Hospital Network. www.schn.health.nsw.gov.au

This is the website for the Children's Hospitals in and around Sydney. It has information, fact sheets and links to resources about ABI.

BRAIN INJURY WEBSITES

Brain Foundation. http://brainfoundation.org.au/

An Australian charity dedicated to funding research into neurological disorders, brain disease, and brain injuries.

Brain Injury Australia. http://braininjuryaustralia.org.au

An organisation funded by the Federal Government that represents all Australians with ABI whatever the cause.

Brain Injury Association of America. www.biausa.org

A USA based site that acts as a clearinghouse of community service information and resources. The Brain Injury Association of America and its affiliates work to reach the millions of individuals living with the "silent epidemic" of brain injury.

Brainline. www.brainline.org/

An American multimedia project offering information and resources about TBI.

BrainLink. www.brainlink.org.au

A Victorian-based service dedicated to improving the quality of life of people affected by acquired disorders of the brain.

Lash and Associates Publishing/Training. www.lapublishing.com

This site provides information and resources to help families, survivors, clinicians, teachers, advocates and counsellors understand the special needs of children, adolescents and adults with brain injury.

LEARNet Problem-Solving System and Resource website. www.projectlearnet.org

A resource for teachers, clinicians, parents, and students by the Brain Injury Association of New York State, which contains useful resources for helping children with brain injury in school and at home. The link to Project Learn has helpful tutorials on a range of issues related to TBI.

Synapse. http://synapse.org.au/

Synapse (formerly Brain Injury Association of Queensland Inc.) is a nation-wide association that aims to reconnect the lives of those affected by brain disorders. This now encompasses the Brain Injury Association of NSW, with the two services unified under the Synapse brand.

BOOKS / ARTICLES / PUBLICATIONS

Anderson, V., Spencer-Smith, M., & Wood, A. (2011). Do children really recover better? Neurobehavioural plasticity after early brain insult. *Brain*, *134*, 2197-2221.

Association for Children with a Disability (2011). *Growing together: A parent guide to supporting siblings of children with a disability.* Hawthorn, Victoria: Author. Available from: http://acd.org.au/growing-together-resource/

Bonner, C.H. (2009). Children with traumatic brain injury: A parent's guide (Helping your child adjust). Available from: http://www.brainline.org/content/2009/06/children-with-traumatic-brain-injury-a-parents-guide-pageall.html

Brainlink. (n.d.). For those that care: A practical guide for families of people with neurological conditions or acquired brain injury. Available from: http://www.brainlink.org.au/page/37/carers-guide

Brock University and the Ontario Brain Injury Association. (2003). *Educating educators about ABI: Teaching classroom teachers how to accommodate students living with the effects of ABI.* Available from: www.abieducation.com/binder/English/chap2.html

Goldenring, J.M., & Rosen, D.S. (2004). Getting into adolescent heads: An essential update. *Contemporary Pediatrics*, *21(1)*, 64-90.

Headway Victoria Acquired Brain Injury Association. (2005). *Changed lives: Brain injury information kit*. Melbourne: author. Available from: http://brainlink.blob.core.windows.net/assets/uploads/files/ABI%20Kit%20PDFs/ChangedLives.pdf

Klonoff, P.S. (2014). *Psychotherapy for families after brain injury.* New York: Springer. (Chapter 3: The impact of brain injury on different family members)

Kvols, K., & Hall, H. (2013). *Bedtime without struggling*. Available from: http://positiveparenting.com/bedtime-without-struggling/

Murtagh, J. (2007). What about me: Perceptions of support by siblings of children with an acquired brain injury. Completed for the Motor Accident Authority Project No. 02/850

http://www.lifetimecare.nsw.gov.au/ data/assets/pdf file/0018/23193/What About Me.pdf

Ollendick, T.H., & Schroeder, C.S. (Eds.). (2003). *Encyclopedia of clinical child and pediatric psychology*. New York: Springer.

Sydney Children's Hospital Network, Kids' Health (2016).

- Concussion. Available from: https://kidshealth.schn.health.nsw.gov.au/concussion
- Mild Head Injury and Concussion. Available from:
 http://www.schn.health.nsw.gov.au/files/factsheets/concussion and mild h
 ead injury-en.pdf

Ylvisaker, M. (1998). *Traumatic brain injury rehabilitation: Children and adolescents* (2nd edition). Boston, MA: Butterworth-Heinemann.

Ylvisaker, M. & Feeney, T. (1998). *Collaborative brain injury intervention: Positive everyday routines.* San Diego, CA: Singular Publishing Group.

RESOURCES FOR EDUCATION

Department of Education, Training and Employment and Women's and Children's Hospital. (2000). *Children with acquired brain injury: Planning and support for schools and preschools and childcare services.* Adelaide: author.

A number of parents have recommended the following educational booklets (published by Dorling Kindersley Publications) that have worked for them when they support the student at home:

- Maths made easy
- English made easy

Available from: https://www.dk.com/au/explore/education/maths-and-english-made-easy/

RESOURCES FOR PARENTING

Carr-Gregg., M. & Shale., E. (2002). *Adolescence: a guide for parents.* Sydney: Finch Publishing,

Not everything is a result of the ABI. This is a great little Australian book that helps parents to create an environment for young people where they feel safe, valued and listened to!

Faber, A. & Mazlish, E. (2001). How to talk so kids will listen and listen so kids will talk. London: Piccadilly Press.

A wonderful book every parent should read. It is well set out with great real life examples you will relate to. Each chapter contains a concise summary and there are some great visual graphics as well.

Ferber, R. (1999). Solve your child's sleep problems. London: Dorling Kindersley.

Positive parenting network. www.parent.net.au

This is a great site about parenting. It's a wonderful resource with lots of practical, realistic ideas, courses, written resources and encouragement.

Parenting SA. www.parenting.sa.gov.au

Contains guides for parents on a wide variety of topics.

RESOURCES FOR RELAXATION

Garth., M. (1991). *Starbright: Meditations for young children.* Harper-One. Garth., M. (200). *Sunshine: More meditations for children.* Harper Collins.

Some parents have found these useful in helping their children with sleep problems and anxiety.

Relaxation imagery for children and adolescents:

- Butterfly dreaming This CD contains tracks suitable for ages 4 to 10 years.
- Cool karma This CD contains tracks suitable for ages 10 to 18 years.

Available from:

Denise Allen

432A The Entrance Road, Erina Heights, NSW 2260

Ph: (02) 4365 1666; Fax: (02) 4363 1664

Email: deniseallen@nlc.net.au

Civardi, A., Petty, K., Dunbar, J., & Somerville, L. *Night lights: Stories for you to read to your child to encourage calm, confidence, and creativity.* Lime tree kids books. A collection of 20 narrative-based meditations, designed for parents to use with children aged 4-8 years.

RESOURCES WITH PERSONAL ACCOUNTS

Durham, C. (1997). *Doing up buttons.* Melbourne: Penguin. *A personal and practical account of one woman's journey with head injury.*

Dolman, G. (1999). Light at the end of the tunnel: Experiences and thoughts of people who sustained a brain injury in childhood. Sydney: Brain Injury Association of NSW.

Koenig, C. (2008). Paper Cranes. New Zealand: Exisle.

Orr, W. (1996). Peeling the onion. St Leonards, NSW: Allen and Unwin. A terrific book for parents and older teenagers. It would be especially good for friends to read to get a better insight into the issues.

RESOURCES ABOUT SEX AND SEXUALITY

Family Planning NSW. (1997). *All about sex.* Available from: https://www.fpnsw.org.au/

Not specifically written for people with ABI but contains some useful and well-presented information.

Dawson H, Hendy J, Simons M, Epps A. (1999) Sexuality and acquired brain injury in children and adolescents: A guide for health professionals and the family. Sydney: New Children's Hospital.

This is a useful book that brings together a lot of information and contains lots of personal reflections and case studies.

Simpson, G. K. (1999). You and Me. An education program about sex and sexuality after traumatic brain injury (2nd ed.). Sydney: South West Sydney Area Health Service

Simpson, G. K. (1999). You and Me. A guide to sex and sexuality after traumatic brain injury (2nd ed.). Sydney: South West Sydney Area Health Service.

OTHER RESOURCES

Neuroscience for kids. www.faculty.washington.edu/chudler/neurok.html

This is a terrific site designed for students and teachers who would like to learn about the nervous system. There are lots of games and interactive activities. It could be helpful for siblings trying to understand what has happened.

Queensland Studies Authority. www.qsa.qld.edu.au

This site has general information about ABI and specific information targeted at teachers.

St Luke's Innovative Resources. www.innovativeresources.org

This site contains great cards, books, stickers and other resources that celebrate the strengths in people. Great to play with and get discussion going about feelings.

Paediatric brain injury services in NSW

Inpatient Services	Phone	Address
Sydney Children's Hospital Network - Westmead	(02) 9845 2132	Cnr Hawkesbury Road & Hainsworth Street Westmead NSW 2145
Rehab2Kids, Sydney Children's Hospital (Randwick)	(02) 9382 1590	High Street Randwick NSW 2031
Kaleidoscope Paediatric Brain Injury Rehabilitation Team (John Hunter Hospital)	(02) 4925 7963	Kookaburra Circuit New Lambton Heights NSW 2305
Community Services	Phone	Address
South West Brain Injury Rehabilitation Service (Albury)	(02) 6041 9902	335 Reservoir Road Lavington NSW 2641
Southern Area Brain Injury Service (Goulburn)	(02) 4823 7911	PO Box 274 Goulburn NSW 2580
Illawarra Brain Injury Service	(02) 42238470	8 Eyre Place Warrawong NSW 2502
Mid Western Brain Injury Rehabilitation Program (Bathurst)	(02) 6330 5114	Heritage Building Bathurst Health Service Howick Street Bathurst NSW 2795
New England Brain Injury Rehabilitation Service (Tamworth)	(02) 6767 8350	Dean Street Tamworth NSW 2340
Mid North Coast Brain Injury Rehabilitation Service (Coffs Harbour)	(02) 6652 2856	39 Victoria Street Coffs Harbour NSW 2450

Paediatric brain injury services in Victoria

Other nearby services (based in Victoria)		Phone	Address		
Victorian Paediatric Rehabilitation Service (VPRS) Provide interdisciplinary rehabilitation for children with congenital, developmental, or acquired conditions that require rehabilitation. There are 8 sites across Victoria, the two covering North Victoria are:					
Goulburn Valley (Hume region)	(03) 5832 2322		Goulburn Valley Health Graham Street Shepparton VIC 3630		
Bendigo (Loddon Malle region)	(03) 5454 6001		Bendigo Health John Lindell Mercy Street Bendigo VIC 3550		
Melbourne City Mission Statewide Paediatric ABI Service	1800 343 287 (Disability Services Intake)		Head Office: 164-180 Kings Way South Melbourne VIC 3205		
Assist those working or living with children and young people (aged 0-18 years) with an ABI.					