NRH
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An tOspidéal Náisiúnta Athshlánúcháin

Talking to Children about Brain Injury:

A practical guide for families

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Foreword

This guide was developed as part of a suite of resources for the Brain Injury Programme in the National Rehabilitation Hospital, 'Supporting Child Relatives of Adults with Acquired Brain Injury: A Resource' was published in 2018, and is a resource for staff working with patients with an acquired brain injury and their families. It is accompanied by a workbook for children 'What's the Story? When someone in your family has a brain injury', which can be given to children, or to parents to help them support their children.

This guide 'Talking To Children About Brain Injury: a practical guide for families' is the next installment, and is aimed at parents with a brain injury and their spouse or partner. It includes information on the impact of brain injury on children and the family; tips and advice on how to help children; and resources to support children. It also includes some case examples of the kind of challenges facing children of parents with acquired brain injury.

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Impact of Acquired Brain Injury, Including Stroke, on Children and all the Family

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Impact of Acquired Brain Injury, Including Stroke, on Children and all the Family

While some children cope very well following their parent's brain injury, some children can be affected in other various ways.

- Children have to try to understand and cope with the symptoms of brain injury, such as emotional or behavioural changes in their parent.

- They may also have to get used to role changes within the family, which can change the relationship with their parents. For example, the non-injured parent may have to assume responsibility for household management and childcare, while the injured parent may assume a more dependent role, or the child may have to take on some care tasks and assume a more adult role within the family.

- There may also be social consequences following the brain injury. For example, families may have financial difficulties or unemployment resulting from the brain injury. This can lead to feelings of insecurity and uncertainty for children.

- Children may feel like they've lost their parent even though they're still there, especially if the parent has changed emotionally or behaviourally.

- Children may have to adjust to new living arrangements, such as moving in with grandparents, or their injured parent moving out of the family home.

- If the injured parent is less well able to fulfill his or her parenting role, for example by giving less attention to children, or less boundary setting, this can lead to an increased risk of children being stressed and upset.

- The non-injured parent may also be stressed if they have to try to fulfill the role of both parents, which may take its toll on that parent and lead to more stress for all of the family.

- Children cope in different ways. Some children take on more responsibility in the home and in care tasks; and they feel empathy for the non-injured parent. Some may display anti-social behaviour at home and in school, such as temper tantrums, disobedience, anger and hostility. Others may experience low mood, poor self esteem, inability to enjoy previously enjoyed activities, or may have feelings of loneliness and isolation.

- Peer relationships can help children cope with their parents' brain injury. Relationships with friends can help children to maintain a sense of normality and continuity between their lives before and after brain injury. Friendships provide a break for children from their family and give them space to be 'normal'.

Impact of Brain Injury on Parenting

If you or your partner has a brain injury, there are a number of ways in which it might be more difficult to parent your children. Not every parent will have all or even many of these difficulties, but the table on page 11 gives an idea of the potential difficulties you might experience, and how your children may be impacted in day to day life. Children have to try to understand and cope with the symptoms of brain injury, such as emotional or behavioural changes in their parent.

Problems arising from brain injury	Impairment	Possible consequence for child. Examples include
Cognitive	Attention difficulties	When children bring friends home from school, you may not cope well with the noise and extra demands this entails
	Long term memory problems	You may forget the details of important events in your child's life such as their birth or early years
	Everyday memory problems	You may forget the route to school, or may forget to give your child a school lunch
	Communication and Language Skills	You may not be able to help your child with homework; it may influence you disciplining your child as you may not be able to explain the reason for the disciplinary action; you may not be able to 'get the joke' or tell when your child is lying
	Executive functioning difficulties	You may not be able to supervise your young children as well as you used to; 'play fighting' may become too rough; you may leave the house with your baby and forget to bring nappies or other items
Behavioural	Irritability and temper	You may not be able to control your temper and become annoyed with children very quickly if they are noisy
	Impulsivity	You may change a decision that is important to your child without explaining why
Emotional	Depression or low mood	You may spend less time with your child due to believing you're not a good enough parent
	Anxiety or Depression	You may worry excessively about your child's safety; you may want the house to be immaculately tidy and find it difficult to tolerate children's toys left lying around
Physical	Mobility	You may be unable or find it difficult to run and play with your child; there may be limited family activities that the whole family can do together
	Co-ordination	You may be unable to help small children fasten buttons or tie shoelaces
Social and Practical	Driving	It may be difficult to plan activities with your child if you cannot drive; you may have to rely on others for assistance
	Epilepsy	You may not be able to supervise a small child, depending on the likelihood of seizures

Children’s Understanding of Brain Injury

Depending on their age and stage of development, children have different levels of ability to understand difficult concepts such as brain injury and behavioural symptoms. Below is some information on children at various developmental stages and how they can understand their parent’s brain injury, as well as the effects of the injury on their behaviour. It is important to note that some children may not demonstrate any of these effects on behaviour, while others may exhibit different effects not mentioned here.

Developmental Stage	Level of Understanding	Effects on Behaviour
Infancy (0-2 years)	Understands simple concept of ‘hurt’ or ‘sick’	Unsettled, disturbed sleep, feeding difficulties
Early Childhood (2-6 years)	Understands visible symptoms; egocentric thinking – will blame themselves	Clingy, temper tantrums, new fears, loss of skills (bed wetting)
Middle Childhood (7-12 years)	Understands all impairments but believes full recovery is possible	Sad, withdrawn, increase in fears, anger
Adolescence (13-18 years)	Understands complexities and needs emotional support to cope	Anger, mood swings, fatigue, resistance to rules and boundaries

Babies and Infants (up to age 2)

Babies and infants are unable to understand complex concepts but can understand being ‘hurt’ or ‘sick’ from about 6 months onwards. They are also more aware of a parent being absent and can be distressed by this. Babies show problems such as unsettled behaviour, disturbed sleep, and feeding difficulties at times of family stress.

Pre-schoolers (up to age 6)

Pre-schoolers have a better understanding of what an injury is, but will likely struggle to understand ‘unseen’ symptoms of brain injury such as poor concentration. They will also find it difficult to understand problems being long term or permanent and will likely expect the adult to make a full recovery.

Pre-schoolers have ‘egocentric’ thinking and view everything in relation to themselves. They are therefore vulnerable to blaming themselves for the accident, and may believe that their ‘naughty’ behaviour on a particular day caused their parent’s accident.

Some pre-schoolers may also believe that they will ‘catch’ the injury from their parent and so may avoid them. Pre-schoolers can become clingy, may have more temper tantrums, and may lose some of their previously acquired skills. They may also develop new fears, for example, fear of the dark.

School-age Children (6-12 years)

Young children have a better understanding of brain injury and will understand both 'seen' and 'unseen' symptoms if they are clearly explained. However, they may still need help in understanding the long term nature of brain injury, as they are still likely to expect their parent to make a full recovery.

Young children worry about what their friends think as they don't want to be different. They may be teased about their parent being 'odd' and so will need help in knowing what to tell their friends about the injury.

Some children, like pre-schoolers, may also blame themselves for the injury, and may not know how to behave 'normally' towards their relative as they may believe they must not misbehave at home if they want to help their relative recover.

School age children can become sad and withdrawn, and their school work may suffer. They can show an increase in fears and phobias. They can also show anger towards the injured person, and complain of physical problems, such as stomach aches.

Teenagers (13-18 years)

Teenagers can generally comprehend the complexity of brain injury, and can therefore be told about its severity, the extent of recovery, and permanence of the injury. However, they will need considerable emotional support to cope with this information.

Teenagers may respond with resentment and anger. They can become tired as they have to take on additional household tasks. They may show an increase in mood swings and oppositional behaviour, and resist family rules and boundaries.

Your own adjustment

It can be hard enough dealing with the impact of brain injury on your own life, without thinking about how to explain circumstances to your child that you never thought would happen. Your child may be sensitive to your feelings, maybe more than you realise. It is important to acknowledge your own emotions before you speak with your child.

It is natural to feel an array of emotions after a brain injury. However, be mindful that a child can misconstrue overwhelming emotions, such as anger and sadness, as being their fault. Similarly, a child can translate their anxiety and worry as the problem being worse than it is.

It is important to be calm, honest and factual when speaking with your child to reduce their anxiety and encourage openness. It is helpful to answer your child's questions honestly and in an age appropriate way. It is okay to be upset in front of your child, just make sure that your child is reassured that they are not the cause of your upset.

If you are finding it difficult to talk to your child it may be because of your own understanding of what has happened, or your fears and concerns. It could be helpful to have a family member, friend or healthcare professional to support you to talk to your children about your injury.

While you may feel alone during the initial stages of injury, many other families have been in this same place. Hearing about the experiences, challenges and successes of other families affected by brain injury could be helpful when considering how to talk to your child about your own or your partner's brain injury.

If you think that this would be helpful for you and your family, then contact the hospital or community social worker. You could join a family support group or get in touch with a peer support service. Don't forget that every family is different, and what works for one family may not be the right fit for your family.

The family members who are at home

It may be difficult to find a balance between keeping routines, visiting and supporting your injured family member in the hospital and keeping on top of everything you need to. There may be days when you are unable to do much at all and are feeling overwhelmed. This is okay. You can only do your best, so sometimes taking a break is the best option.

We all need time to rest!

Being able to look out for the needs of a child effectively involves being able to look after your own needs too. Don't be afraid to ask for help. No one can look after a child on their own all of the time. Everybody needs a break, and this is normal. Having a break is not a sign that you cannot cope, but rather an indication of your strength to pool the resources available to you, to give you and your family the best support available.

If a friend or family member you trust can look after your child for a few hours or even a day, take this time for yourself. If you don’t have someone you can call on, consider asking about a local babysitter or child minder. It is very important to take some time out regularly, and this way you will be better able to give your children the love and attention they need. While caring for children is a special job, we all need time for ourselves.

Often during a family crisis, relationships with people will change. Some people may feel overwhelmed by the support or lack of support offered by friends and family. It is important to communicate your own support needs. If you find this difficult, a close family member or friend may be able to organise this on your behalf. Families might feel obliged to spend as much time as possible at the hospital. If you need some time out that is more than okay.

Case Examples

John

John was 38 when he had his traumatic brain injury. His wife Alice and 4 year old daughter Cathy were very upset. Alice spent a lot of time in the early days in the hospital with John, which was very upsetting for Cathy as she felt she had lost both of her parents.

Alice's friends and neighbours were very supportive at the beginning and helped to look after Cathy and keep her in a routine. Cathy asked all the time to see her father in hospital, and after thinking about it and discussing it with hospital staff, Alice agreed to let Cathy in to visit. She was very happy she did this as although it was upsetting, Cathy felt included and not left out. She got to know the doctors and nurses and was happy that they were looking after her daddy. Telling Cathy the truth was important for both her and Alice and helped to keep their trusting relationship.

Now that John is home, Cathy is protective of her dad and tries to help a lot. Alice has to remind her that she can play with her friends and doesn't have to be a carer as she is only a child and should be having fun. But she also wants to make sure Cathy feels important in the family so she allows Cathy to help with running errands.

For Alice, it was a very stressful time, and she tried to be strong for Cathy as well as her husband. She really appreciated the help of friends and having the opportunity to sometimes take some time for herself. She knows that if she takes care of herself, she will be better able to take care of her daughter. She also goes to Headway and ABI Ireland for support, and accepts help when it is offered.

> **Telling Cathy the truth was important for both her and Alice and helped to keep their trusting relationship.**

Erica

Erica was 45 when she had her stroke. She was married to Patrick and they had three young children – aged 2, 5 and 7. Both Erica and Patrick were teachers, and had supportive family. The family helped to take care of the children while Erica was in hospital. Patrick tried to continue working as well as visiting Erica and caring for the children.

The children had lots of questions about what happened to their mum.

When she started to get better they got very confused about why their mum was so tired even though she looked fine and was walking and talking as normal. They thought she was ‘cured’ and wanted to be able to play with her, but she often said she was tired and needed to rest.

The therapists in the hospital met with the children and explained to them about fatigue and how their mum needs lots of rest. They made a chart for the wall with the picture of a battery, so that they could ask their mum regularly whether her battery was low or high, and then they knew when she needed a rest.

The children also told the therapist in the hospital that they thought one of them caused Erica’s stroke as they slept in her bed the night before and had pressed their elbow against her neck all night. The therapist explained how the stroke happened and that it could not be caused by pushing against someone’s head or neck. This reassured the children and they no longer felt guilty.

Tom

Tom was 50 when he had a traumatic brain injury. He and his wife Aoife had 4 children – aged 2, 6, 9 and 12. Tom was self-employed so while he was in hospital and after he came home, money was very tight for the family as he was not able to work. Aoife tried to run the family business as well as minding the children. She did not have any family to help but had some support from friends.

Aoife was worried about her oldest daughter Jill because she got very angry sometimes that the family didn't have the money to go to the cinema, or to buy the computer games that all her friends were talking about. Jill sometimes shouted at her father for being sick, and shouted at her mother for working all the time yet not giving her any money.

Aoife spoke to the rehabilitation social worker about Jill, who met with Jill and explained about brain injury. She also encouraged Jill to talk to her friends about her dad's brain injury and explain to them what was happening in her family. Jill also agreed to meet with a local counsellor, which the social worker arranged through the GP, and she felt much better being able to talk about her feelings.

The social worker also helped the family with applications for financial supports, which took some of the pressure away from Aoife, and allowed them to engage in some fun activities together as a family.

Aoife encouraged Jill to talk to her friends about her dad's brain injury and explain to them what was happening in her family.

Section 2

Helping Children Cope with Brain Injury

Section 2

Helping Children Cope with Brain Injury: Tips and Advice

Give honest age-appropriate information to children to help them understand brain injury, and give them an opportunity to express their feelings and concerns

- It is important when explaining symptoms to your children that they are addressed at a level they will understand. Sometimes the most upsetting thing for children is not the brain injury itself, but the feeling of not knowing what is happening and feeling they are being excluded.

- Children who are not given enough information will usually assume the worst and will have created an image in their head of the future, which is often far worse than the reality. Giving children the opportunity to express their feelings is also important in helping them to adjust to you or your partner's injury, thereby reducing potential future behavioural or other difficulties for the whole family.

- Being open and honest with your children helps them feel respected and loved.

- Children can often have misconceptions about brain injury symptoms, and would benefit from regular updates on how their relative is doing. For example, fatigue is a common symptom of brain injury, but children might think that you are just a little tired and will be ok after a short rest.

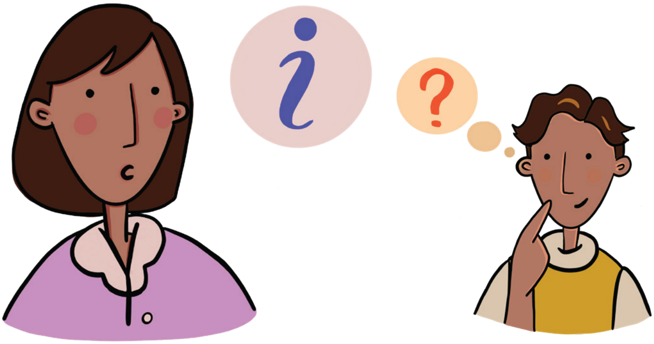
  The full impact of fatigue should be explained to children in order to avoid them putting pressure on you to engage in activities you are unable to complete.

- Giving children regular updates helps to ensure they feel included in the process, and ensures they have an understanding of your condition and progress.

- Many children, particularly young children, blame themselves for their relative's brain injury, and think their behaviour on a particular day contributed to the accident or event. This impacts how they behave towards that relative, with some children trying to be perfectly behaved all of the time, or some not knowing how to act 'normal' around their relative.

- Children look to adults to gain a sense of the world and how to react to events. If children see other members of the family coping well and adjusting to their relative's injury, this will help them to also try to deal with the injury in a positive way. Family life will undoubtedly change once a member has a brain injury.

  In the initial acute hospital stage, it is likely that children have been looked after by various family members and friends. Children may also have been taken out of school for hospital visits.

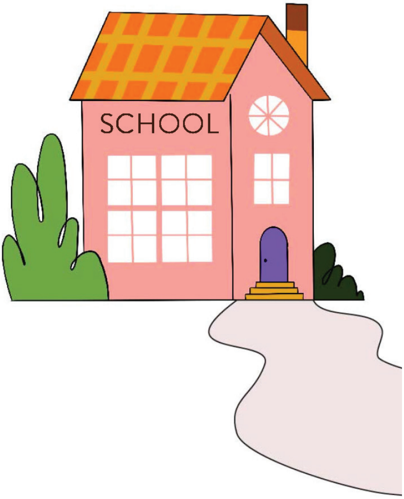


- During the rehabilitation stage, it is important that life for children returns to some form of normality, with a return to school, and if possible only one or two 'main' carers. Any change is difficult for children as they like routine and boundaries.

  While some changes are unavoidable, it is important to instil some routine and return to boundaries in order to help them adjust to a 'new normal' life. It is also important they continue to engage in any after-school activities; research has shown that peer support is beneficial to children's sense of wellbeing.

- Children spend a significant amount of time in school. The influence of friends and teachers can be considerable. There is therefore the potential for a huge resource within the school to provide support and an outlet for children.

  Teachers are also well placed to observe any changes in children and can alert family to the need for extra supports, such as counselling.



Listen to your children

- Give children time to make their message clear and show them you respect how they feel. Show this by making good eye contact, and giving them time to express their concerns or questions.
- Be encouraging of their questions and pick a time when there are minimal distractions.
- Children usually talk about difficult or painful things in a roundabout way.
- Children need assurance from adults that it's okay to talk about upsetting things.
- Sometimes children will have physical symptoms that will indicate worry or stress – for example your child might say "I don't feel well" or "I have a sore tummy".
- Help your child work out their for coping with a problem, talk with them about which ideas might help or not, and why.

Encourage regular visits to the injured parent when they're in hospital, as well as telephone calls, emails, letters, Facetime, children's pictures

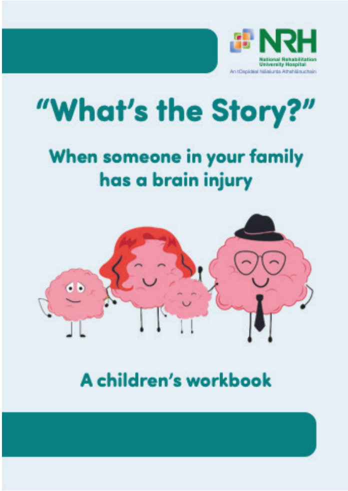
As with the need for regular updates, your child will also benefit from regular contact with you or your partner, either through hospital visits, email and Facetime calls. If children can see you and engage with you, this will help to reduce their fear and anxiety, but it will also help to maintain the bond between you.

Ask if children can observe and participate in therapy sessions where appropriate, but be careful to ensure children don’t feel they need to be mini carers or therapists

Attending therapy sessions can really help children to understand the nature of your impairments or disability. As well as giving them the opportunity to learn how to help you on a practical level, this can also make them feel useful and important. It is important however, to make sure children do not feel they have to become carers or ‘mini-adults’ in the family.

Common questions asked by young children (up to age 12 approximately) and how to answer them

See workbook **“What’s The Story?” When someone in your family has a brain injury** which serves as an accompaniment to this booklet. The workbook can help to explain brain injury to children, while also allowing them the opportunity to discuss their own family situation and their feelings.



NRH

“What’s the Story?”

When someone in your family
has a brain injury

A children’s workbook

Common questions asked by teenagers, and how to answer them

Is important to allow them to come with questions and give them the opportunity to express their feelings. The questions below are just a guide. Teenagers may want to research brain injury themselves, and some books can be very helpful, such as Jo Johnson's (2011) 'My Parent has a Brain Injury: a guide for young people'.

Teenagers should also be encouraged to speak directly to staff, and depending on their age, should be given the opportunity to see staff on their own as they may feel more comfortable asking questions without their parents being present.

What is a brain injury?

A brain injury happens when the head and brain get hurt or damaged. A brain injury can also be called a head injury, a traumatic brain injury (TBI) or an acquired brain injury (ABI).

Who can get a brain injury?

Anyone of any age can have a brain injury.

How does a brain injury happen?

Most brain injuries happen because of an accident, such as a car accident, a fall, or if a person is hit by something. Many children and young people blame themselves for the accident and feel that somehow the accident happened to 'pay them back' for things they had done wrong. They also sometimes think that they might have been able to prevent the accident happening (for example by having done something differently on the day).

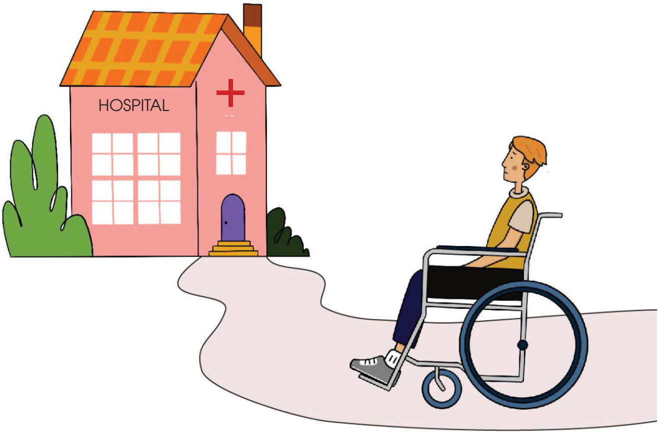
It is important to know that your relative's injury did not happen because of anything you did and they would not want you to worry about this.

What happens when someone has a brain injury?

Most people with a brain injury go to hospital, where staff will assess how severe the injury is and decide on the best way to treat them. Some people can go home quite quickly if their injuries are not serious. Those who have more serious injuries will have to stay in hospital. They will usually need more tests (such as brain scans), be monitored and maybe have an operation on their brain. They might spend some time in intensive care before moving to a ward.

During this time, they may be unconscious, confused, or attached to lots of equipment. This is a normal part of recovery but can be upsetting and frightening.

Some people with brain injuries remain in hospital for weeks or even months. They may have rehabilitation in another hospital before going home, or attend hospital clinics from home. Recovery usually takes a long time.



Unfortunately some people do not recover completely and continue to have problems when they get home. A small number of people do not recover from their injury and are unable to return home to live. Instead they have to live in a facility such as a nursing home where they will be cared for by trained staff. This can be very sad and difficult for all of the family.

Most people do not die because of a brain injury, but a small number do. This is very hard for everyone in the family and they will need a lot of support to cope with this.

What kinds of problems can people with brain injuries have?

People can have a wide range of problems such as:

Physical – for example, being unable to walk or use their arms

Cognitive – a person may have poor memory or concentration

Emotional – this can include sadness, worry, depression, anger

Behavioural – such as being more aggressive, shouting, sitting still and doing nothing

Relationship problems – for example, arguing with relatives, ignoring others.

Sometimes these problems can be very severe, and the person cannot go back to work or look after the family like they used to. It can be very difficult to understand these problems, as the person can look exactly the same but behave differently. Their behaviour can be upsetting, or cause embarrassment or anger, and you might not want your friends to visit the house and see them like this. Try to remember that they have changed because of the accident and that they still love you, even if it doesn't always seem like it.

> **Sometimes the person with a brain injury can look exactly the same but behave differently.**

Do brain injury problems recover?

Lots of problems after a brain injury can improve. It can help if you can find ways of 'getting around' problems – such as helping someone remember things by using a mobile phone. However, recovery from brain injury can take a long time, and even after many years, people can still have problems.

It is very hard for doctors to know who is going to get better and how long it will take. Usually we just have to wait and see what happens.

How does it feel to have a brain injury?

We cannot know for sure how someone with a brain injury feels if we haven't had one ourselves. But from what we can see, people with brain injuries are often upset and distressed about what has happened to them and if they will get better. They can also be sad or angry about it all.

If they have memory problems, they can be quite confused about what is happening. Some people don't appear to worry at all about their brain injury. This could be because they don't fully understand what has happened to them, or it could mean that they have found a way to cope with it.

How do young people feel when someone in the family has a brain injury?

Everyone reacts differently to brain injury. Some young people feel ok about it and get on with their normal life. Others get very worried and sad and find it hard to get on with their normal activities. For example, some people find it hard to go to school and do their homework. They may not be able to concentrate because they are worried. Sometimes friends can ask difficult questions that are hurtful or hard to answer.

Some young people argue more with others in the family, as they feel worried or angry about what has happened. They might be asked to do extra jobs around the house or 'look after' their injured relative, which can be annoying. The family might have less money so there might be less money to go out with friends, or buy things. This can be upsetting, or even embarrassing with friends.

Sometimes people can feel sad one day, and worried the next. All these mixed feelings can be difficult, but they are very normal, and the good thing is that they don't last forever. It is helpful to talk to someone about them.

Sometimes going to school or spending time with friends can be a break from all the worries, and that can be helpful too.

What can help?

Talking to someone about your feelings and your worries always helps. If you can talk to an adult you trust that would really help. But even confiding in close friends will help you to feel better. Learning more about how the brain works and brain injury can help. Knowledge about brain injury can help make it easier to cope with. Also, remember that none of this is your fault.

Sometimes going to school or spending time with friends can be a break from all the worries, and that can be helpful too.

Section 3

Resources

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Resources

Where can I get support or further information?

If you are not sure where you can get help, a good place to start is a member of your rehabilitation team. If you are able to articulate what help you need, they can point you in the right direction to get you started. Each member of staff can help:

Medical staff: can provide medical information about brain injury to family members and children.

Nursing staff: can include regular family time on the ward and they realise the importance of maintaining family relationships.

Physiotherapists: can involve children during treatment sessions to explain some of the treatments used and demonstrate the progress their family member has made through activities, such as playing a ball game together.

Occupational therapists: can include children in therapy sessions and activities such as community outings. They can also give support during therapy sessions to maximise independence in caring for and playing with your child.

Social workers: can help involve your child in discharge planning, resourcing, emotional impact of the situation on children, assist to liaise with relevant agencies that your child is connected to, connect to networks to build and assist with coping. Social workers can also provide support to optimise the welfare and safety of your child during stressful times, such as when a parent has a brain injury.

Psychologists: can help to focus on developing your child’s coping skills.

Resources for Children of Parents with Acquired Brain Injury (ABI)

As well as your rehabilitation team, there are many resources available to help – see the list below.

Books

- **A Kid's Guide to Brain Injury** by Headway (www.headway.ie)
- **A Kid's Guide to the Brain** by Sylvia Funston and Jay Ingram
- **Your Amazing Brain** by Jenny Bryan
- **Coma Boy and Superwoman: Two kids with brain injuries beat the odds – their true stories** by Mathilde Backhouse
- **The Human Brain (Science Action Book)** produced by Quatro Children Books LTD
- **Karing Kids: a book by kids for kids about head injury.** Brain Injury Association of Ottawa Valley, Ottawa, Ontario, Canada
- **Pook the hamster wants to know what's wrong with Ben and Lucy's dad** by Laura Bach (Headway UK)
- **My Dad's Had a Brain Injury** by Katie Field
- **Parenting After Brain Injury** by Headway (www.headway.org. uk)
- **My mum's had a Stroke** by Junny Turnstall. Jo Johnson has also written **My mum makes the best cakes and my dad makes the best boats.** These are actually MS specific but are a great way of starting a discussion. They are available from the MS Society.
- **I Know You Won't Forget** by Truly Blessed Ink. A book for readers age 8 and up. Story about a young boy whose mother suffers a TBI.
- **Why Did It Happen On a School Day? My family's experience with Brain Injury**, BIA of Maryland, USA
- **After a Head Injury** by G. Banks

- **Grandpa's Crooked Smile: A story of stroke survival** by Mid-Michigan Medical Center.
- **Brave Mrs Koala** by Robyn Densley
- **Sparky Goes to Grandma's Cottage** by Mathilde Backhouse
- **Susan's Dad: A Child's Story of Head Injury**, by Leif E. Leaf.
- **Elvin the Elephant Who Forgets** by Heather Synder
- **'A little book of suggestions...' - A book of suggestions for children whose parents have a brain injury**: produced by Regional Community Brain Injury Services, Ontario
- **When a Parent has a Brain Injury; sons and daughters speak out**, by M. lash
- **What's up Tamara;** by Medikids
- **Tim - Tron**, by Ian Ray and Garry Parsons

Websites

Neuroscience Resources for Kids

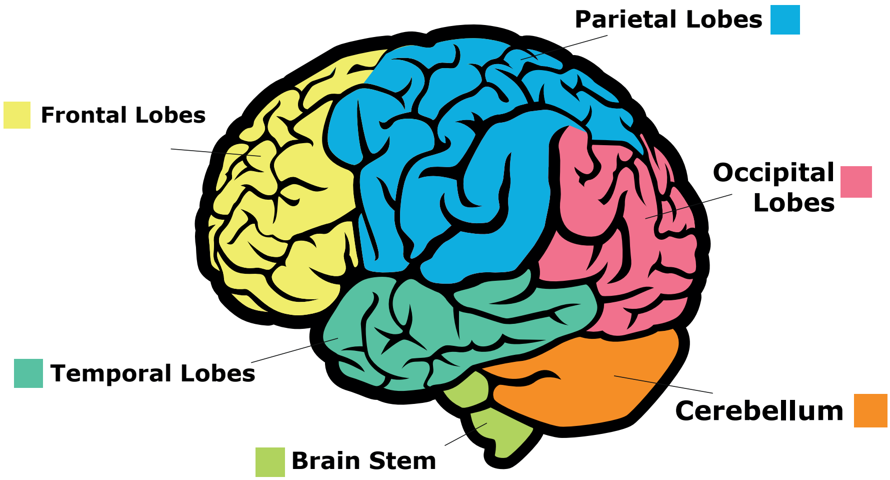
- **www.lapublishing.com**
- **www.strokecenter.org/kids/** An online book that might help children of around five 5 years
- **www.health.qld.gov.au/abios/asp/braincrew/brain_crew_prog**
- **www.thedtgroup.org/brain-injury** BIRT (Brain Injury Rehabilitation Trust)
- **www.medikidz.com** is a UK website which has accessible literature in comic type format for children on topics about medical conditions such as breast cancer, epilepsy, insulin pumps and so on.
- **www.brainline.org**

Games

Rachel's Brain Game

This is a board game to help children share their feelings and thoughts about a loved one who has a brain injury. Two to four players, ages five and up (available via BI Association of America).

Visual tool to help children understand what happens to the body after a brain injury



Damage to Frontal Lobe	Damage to Parietal Lobe	Damage to Temporal Lobe	Damage to Brain Stem	Damage to Cerebellum
Loss of simple movement of various body parts (Paralysis)	Difficulty with drawing objects	Difficulty in understanding spoken words (Receptive Aphasia)	Decreased vital capacity in breathing, important for speech	Loss of ability to co-ordinate fine movements
Inability to plan a sequence of complex movements needed to complete multi-stepped tasks, such as making coffee (Sequencing)	Difficulty in distinguishing left from right	Disturbance with selective attention to what we see and hear	Difficulty swallowing food and water (Dysphagia)	Loss of ability to walk
Loss of spontaneity in interacting with others	Spatial disorientation and navigation difficulties	Difficulty with identification and categorisation of objects	Difficulty with organisation and perception of the environment	Inability to reach out and grab objects

Damage to Frontal Lobe	Damage to Parietal Lobe	Damage to Temporal Lobe	Damage to Brain Stem	Damage to Cerebellum
Inability to express language (Aphasia)	Problems with reading (Alexia)	Difficulty learning and retaining new information	Problems with balance and movement	Tremors
Loss of flexibility in thinking and persistence of a single idea or behaviour (Perseveration)	Inability to locate the words for writing (Agraphia)	Impaired factual and long-term memory	Dizziness and nausea (Vertigo)	Dizziness (Vertigo)
Inability to focus on a task and to filter out distractions (Attention)	Difficulty with doing mathematics (Dyscalculia)	Persistent talking	Sleeping difficulties (Insomnia, Sleep apnoea)	Slurred Speech (Dysarthria)
Mood fluctuations (Emotional liability)	Lack of awareness of certain body parts and or surrounding space (Neglect)	Difficulty in recognising faces (Prosopagnosia)	Locked-in syndrome	Inability to make rapid movements
Difficulty with problem solving	Inability to focus visual attention	Increased or decreased interest in sexual behaviour		
Difficulty inhibiting or controlling a response or impulse (Disinhibition)	Difficulty with motor planning and complex movements (Apraxia)	Emotional disturbance, such as aggressive behaviour		
Reduced motivation, initiation and persistence on activities				
Reduced awareness and insight into difficulties				
Changes in social behaviour				
Changes in personality				

Parent's Handout 1:

How your child may be affected when a relative has a brain injury

How your child may be affected when a relative has a brain injury

A child may not be able to understand why the person seems different. The parent or relative may look the same but react in different ways

There may be role changes in the family that your child has to get used to. You may have to go back to work, for example, while your relative is the person at home

The child may be worried that something will happen to you or other key adults in their lives. They may be protecting you by not sharing their worries

Aspects of your child's life can change because of a serious family illness. You may be unable to afford outings or have the time to bring your child to activities

A child or young person may notice changes in their other parent. You are likely to be tired, distracted and worried yourself.

The child may be missing the 'old' relationship they had with their parent or relative. They may have to become used to this new and changed relationship.

Parent's Handout 2:

How your child may react when a relative has a brain injury

How your child may react when a relative has a brain injury

Your child may be confused as to why the injury happened. They may blame themselves or fear you will also get sick

Your child may feel angry or resentful and their behaviour might be challenging. You may be less able to deal with difficult behaviour due to your own worries

Your child may be worried or anxious but may not be able to explain their feelings. Older children may protect you by hiding fears and worries

Children or young people may not want their friends to know what has happened or that others are talking about it. They may be embarrassed about the situation

A child may appear uninterested in activities and not seem to care about anything. Their mood may be low

The child may be showing signs of upset or challenging behaviour at school. They may lose interest in their school work and their grades may be affected

Parent’s Handout 3:

Why involve your child in the rehabilitation process?

How your child may react w Why involve your child in the rehabilitation process?

Allowing children to visit the hospital can reduce their fear about what is happening to their parent and if they are safe

It is important children see other people can be involved in the care of their parent and they do not take on the role of a carer. This can help children to get on with their own life

A member of the rehabilitation team can see your child and explain about brain injury and answer any questions. The team can advise about community supports for your child

Children can learn practical skills such as how to resume baking with a parent in the O.T. kitchen or how to chat using a communication aid. Involving children has shown to help the whole family cope better

The rehabilitation team can help with ways to connect with children even if they cannot visit; such as weekend leave, photos, FaceTime and days out for special family events

A person with a brain injury will be more motivated to work on goals such as being able to pick up a child from school. This can enhance their ability to resume their role as a mum or dad

NOTES

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