

Helping children and adolescents when a parent has a brain injury - A guide for parents, caregivers and professionals.

This guide was written by Robyn Bett and Associate Professor Jeneva Ohan. The artwork and design was created by Jean Low.

Thank you to all the clients, their families, and staff of the Brightwater Care Group who took part in the qualitative research that is the basis for this guide.

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For further information about this research and to find information and resources for families and young people when a parent has dementia or brain injury, please contact us at <https://brightwatergroup.com/research/>

Brightwater Research Centre
Inglewood, Western Australia

W brightwatergroup.com
E research.enquiries@brightwatergroup.com

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Introduction

A brain injury causes upheaval for the whole family. This guide has been written to help parents, caregivers and professionals understand and respond to children when a father or mother has a brain injury.

Children and young people have less developed coping strategies for stress and life changes than adults. Parents play an important role in the development of their children's coping. When a parent is injured, children are faced with fears and changes they struggle to understand at the same time as losing parental support.

This guide provides a list of actions for adults to help children when a parent has a brain injury.

No one booklet can answer all your questions, but we hope that this information will guide decision-making about children's welfare.

This guide is based on qualitative research with families and professionals and was further informed by a systematic review of, international research and practice. It is not meant as a list of prescribed 'solutions', but rather to be read as information that a family might find helpful in their journey, recognising that each family is different. A list of the resources we consulted is included.

**Our best wishes,
Robyn Bett and Jeneva Ohan**

Summary of our Research

We reviewed resources and literature from around the world. We interviewed professionals, parents, co-parents, children, adolescents and young adults about their experiences. We looked for patterns of meaning and learnt about the experience of parental brain injury for young people.

Young people experience changes in relationships and family roles following a parent's brain injury. Many have strong emotional reactions to all these changes and sometimes feel alone with these big feelings. Children report feeling separate from friends and peers because of changes in their families and find it difficult to talk about brain injury, or to know who to talk to. A parental brain injury leads to the family needing to focus on the injured parent. Focus on children's school progress, sports practice or community involvement can be neglected. Many children experience a sense of loss. We also found children adapting to the changes in their lives, finding new ways to relate and re-developing their vision for the future.

When a parent has a brain injury, the connection with their child is affected. The relationship changes and may need support to be maintained. The child will need help to stay connected from family, friends and peers, and perhaps support from others with similar life experience. It is important that the child has someone to advocate for them, and has access to developmentally appropriate information. Importantly, the child may need professional support or be referred for counselling or mental health services in a timely manner.

Children can be helped to cope when their needs are addressed. The following diagram shows the needs expressed by our participants, and the following pages provide information to help parents, caregivers and professionals recognise and meet those needs.



Help children understand

It is natural and important to want to protect children from life's difficulties. When a crisis happens, working out what to tell children is challenging. This part of the guide will help you find ways to talk with children about a parent's brain injury.

Children have the best chance of feeling stable when they are told what is happening by someone they trust. If children are not told important information directly, they have no one to answer questions and help manage any worries.

Early on children want to know about

“what happened?”

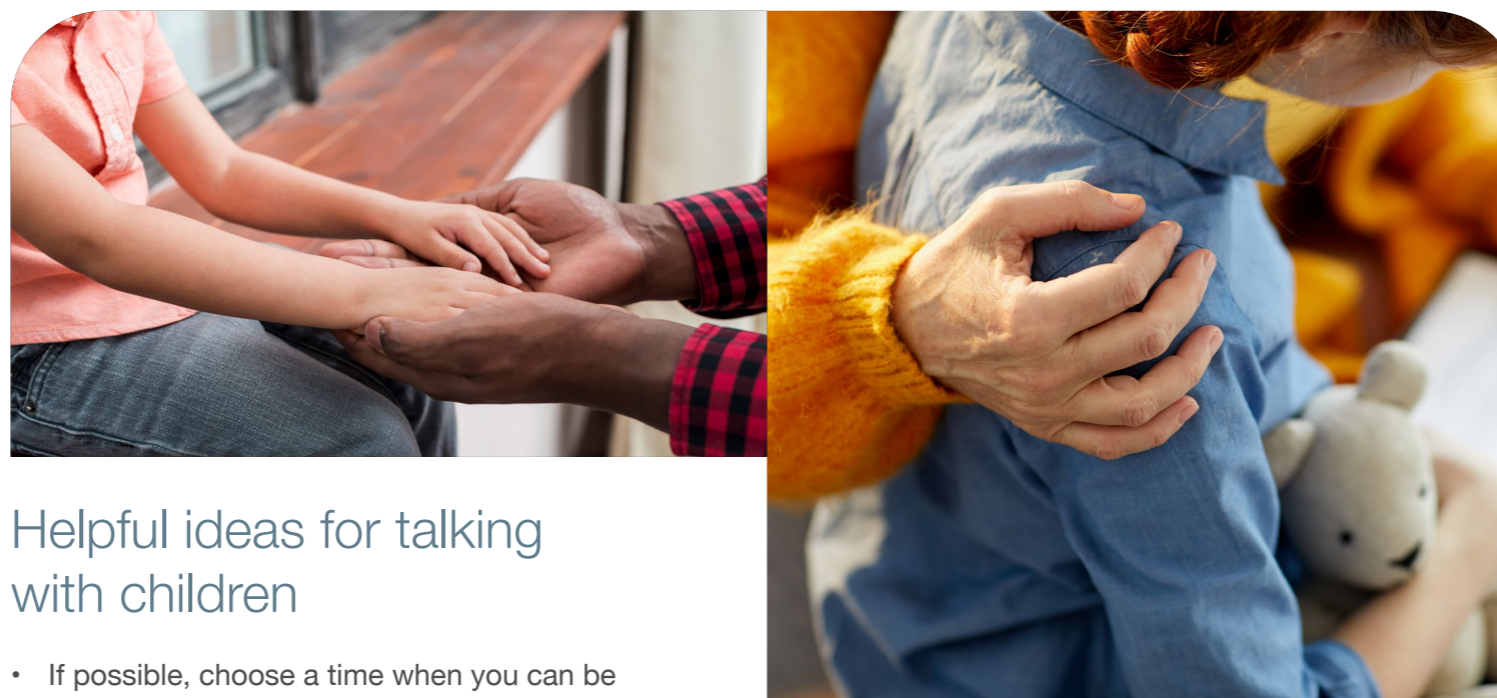
“where is Mum/Dad now?”

“what injuries do they have?”

“are they being looked after?”

“when can I see them?”

“when will they come home?”



Helpful ideas for talking with children

- If possible, choose a time when you can be calm and unlikely to be interrupted. Preferably not bedtime because after big conversations it helps for children to have some play or activity time to discharge feelings.
- It can be useful to have another adult with you for support when you first tell children. That way children will know it is not their job to make you feel better.
- Use language your child can understand and do not provide too many details.
- Children let us know when they are ready to hear more information by asking questions or bringing up topics. Use their clues to help you decide how much to share. Young children usually need less detail than older children.
- It's okay to say that you do not know yet, and that you will let the child know when you find out more.

Be as steady as you can

Children take cues from adult's behaviour. Whatever the child's age, sit with them and talk calmly about the injury so they will be better able to take in what you say.

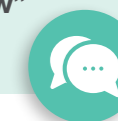
The words that you use do not have to be perfect.

When you talk to children you might cry. This may be difficult for you but it is okay for children to see you cry. Children might cry with you. Naming your feelings will help you keep them in check and help children feel safe.

For example:

“I am feeling confused and know I am showing it”

“I am feeling really sad right now”



Communicating with children about their injured parent is for the child's benefit. During these conversations, focus on how the child is making sense of what you are telling them.

If you need to debrief about your own feelings, do this with other adults.

Fears the parent may die.

It is natural to want to reassure children that an injured parent won't die. However, a brain injury can lead to death and children may have worries about this. If this is relevant to your family, let children know that you will talk to them if they have fears about death. Then they won't have to hide their questions, make up their own answers or take their questions to people they do not know as well.

Combine information with reassurance

When you are helping children understand, you are also reassuring them that you are able to think about their experience. This helps children feel secure.

Reassure kids that:

- **Their parent is receiving care** – Give children examples. It comforts children to know their parent is being looked after.
- **The injury is not the child's fault** - No matter how illogical it seems, a child may think a parent's injury is connected to something they did.
- **They are safe** - Reassure children that they are safe and loved and will be cared for. It is important to remind children that other caregivers are not in danger.
- **Brain injuries are rare** - Children may need reassurance that a bump on their head is not the same as a brain injury.



Talk about the cause of the injury

What happened is often confusing. Explain to children as simply as possible.

For example:

- Child:** What happened to Dad? Why is he in hospital?
- Parent:** Dad fell and hit his head on the road.
- Child:** Is he going to be alright?
- Parent:** I hope so. His brain has been hurt. The doctors are doing everything they can to help him.
- Child:** Can I go and see him?
- Parent:** I'm glad you want to go and see Dad. Let me find out when we can visit.

Sometimes beginning with a question is helpful. For example, "What have you been thinking about Mum's injury?" invites the child to share what they already know and what they are thinking.

It is important that the child learns about the circumstances of the injury from a caring and reliable source, not accidentally from others. Sometimes there are feelings of anger and blame amongst adults, as well as the worry and shock of the injury. When talking with children, try and talk about the person with the brain injury in a caring and respectful way.

Sometimes an injury may be connected to overdose or addiction, and young children may need a concrete explanation of these processes.

Here is an example of a way to talk about overdose.

"Taking medicine as the doctor says is a good thing. An overdose is when someone takes too much medicine, or the wrong medicine and it can hurt their brain, so it doesn't work the way it used to."

Here is an example of a way to talk about addiction.

"Addiction is a condition that causes a person to use more alcohol, drugs or medicine than is safe and sometimes this can hurt a person's brain."

These are difficult conversations to have, and you might find that seeking professional support, such as from a counsellor or psychologist is helpful. There are some resources listed in this guide that might help.

Explain the impact of brain injury

It can be very difficult to predict the long-term effects of brain injury. You can begin to explain what is happening in terms of a process.

For example:

"Your dad's brain has been hurt so there are some things he can't do right now. We don't know what he will be able to learn to do again, and what he won't. We do know it will take a long time and a lot of hard work."

A brain injury is hidden. Young people can see a broken leg, or a scar, but they cannot see a brain injury. Depending on the child's age, it will take time to help a child understand a parent's brain injury.

You can use comparisons that your children are familiar with to help them understand brains and brain injury. Here are some examples.

"The brain is like a computer for the body. When a computer is damaged it can still start but it isn't quite the same, it runs slower or has less memory."

"The brain is similar to the command station of a spaceship. If a meteorite hit the command station, the crew would not be able to control what the spaceship does. If the brain is hurt, it may send out the wrong signals, or no signals to parts of the body. A person with a brain injury may have a hard time walking, talking, hearing or seeing."

Books and online resources can help

Children benefit from age-appropriate explanations of what the brain does and how an injury to the brain can affect a person.

There are books and online resources that can help. There are children's books that go with this guide. A full list of useful resources can be found at the back of this book.

Talk about recovery

Leaving hospital or rehabilitation is an important milestone in the process of recovery, but it can also be a challenging time. Children are likely to have a lot of questions.

“Dad used to be so... “

“When will things get back to how they used to be?”

“Why does my dad talk differently?”

“Why does my mum need someone helping her still?”

“Why can't mum remember anything I just told her?”



Children might find it hard to understand changes in behaviour particularly if the parent looks the same as before the injury. For a child whose parent was injured before they can remember, they may have more questions as they get older.

Professionals can help

While injured parents are in hospital, or receiving rehabilitation services, professionals can help children understand more about their parent's injuries, and find 'work-arounds' for the challenges they face.

We recommend:

- Professionals ask parents and carers for permission to explain to children.
- Parents ask professionals for help with explaining to children.

A preschool child might expect the injured parent to come home and play like they did before an injury. A primary school aged child might wonder why a parent is not going back to work. An adolescent might expect the injured parent to get back to household chores.

Talking about what has changed for children when a parent returns home after injury allows children to acknowledge disappointments and frustrations. Speaking about difficulties can help clear the air, and be part of a process of discovering what can work in these changed circumstances.

“It's a bit sad because my Dad had to get hurt, and he can't be outside for too long.”

- Child



Acknowledge emotional impacts

A child will be supported when caring adults acknowledge that a parent's injury can have emotional impacts on children's behaviour.

Here are some examples where parents are figuring out how a child's experience of a parent's injury might be impacting on a child's behaviour.

In these examples the parents communicate their understanding to help the child feel better.



Example 1 - Matilda

Matilda's Dad had a stroke two years ago and is still attending rehabilitation. It's 7.30 at night and Matilda, age 9, is insisting that her Mum take her to the doctors immediately because she has a sore throat.

Mum says, "Let's see if we can help your throat feel better, and if it's still sore in the morning we'll make an appointment".

Matilda explodes with anger "You don't understand! I have to go to the doctor right now! If you loved me you would take me to the doctors, now!"

Mum, making a guess says, "Matilda, I know that when Dad had his stroke, he needed the doctors as soon as possible. I wonder if you're scared that your sore throat means something very bad is going to happen, and that you need a doctor to take care of you."

Matilda is quiet.

Mum says, "Sore throats are not dangerous. I'll make you a honey and lemon drink, and we'll see how you feel tomorrow".

Matilda nods.



Example 2 - Jack

Jack, age 12 was a keen soccer player. One rainy evening on the way to soccer practice, a car crossed the centre line and hit Mum's car. Jack wasn't injured but Mum was badly hurt, and spent months in hospital. When she came home, she was often tired. Jack begged to give up soccer, saying homework made him too tired for training.

Jack's Dad, making a guess says "Jack, I know you're in Year 8 now and you have more homework than before, but I also wonder if because Mum was taking you to soccer when she had the accident, that you feel guilty about what happened."

Jack, raising his voice, says sarcastically, "You think?"

Dad, keeping calm, says "It must be difficult being reminded of that guilty feeling every time soccer training is on. But Jack, it wasn't your fault."

Jack says, "I really don't want to talk about it."

Dad acknowledges Jack by saying "That's because it's really hard to talk about. I know you loved soccer before the accident. How about I come home early on soccer training evenings, and take you to soccer? Sometimes we might think about the accident and what happened to Mum, and sometimes we might just think about soccer. Either way we'll be together on it. Shall we give it a go?"

Jack nods.



In conclusion

When we talk with children about a parent's brain injury we provide the support they need to make sense of their experience.

As well as giving children the information they need to make sense of what has happened, opportunities for children to say how they are feeling will provide a sense of connection and promote feelings of safety.

Where possible, keep children's normal routines in place as these can be comforting in times of change.

This finishes our section on helping children understand. The next section is about connections.

Support connections



This section is about supporting connections when a parent has a brain injury.

Whether a child sees a parent daily, on weekends, or rarely, parents have a special place in children’s minds and hearts. When traumatic injury happens to a parent, children are comforted when connections are acknowledged and maintained.

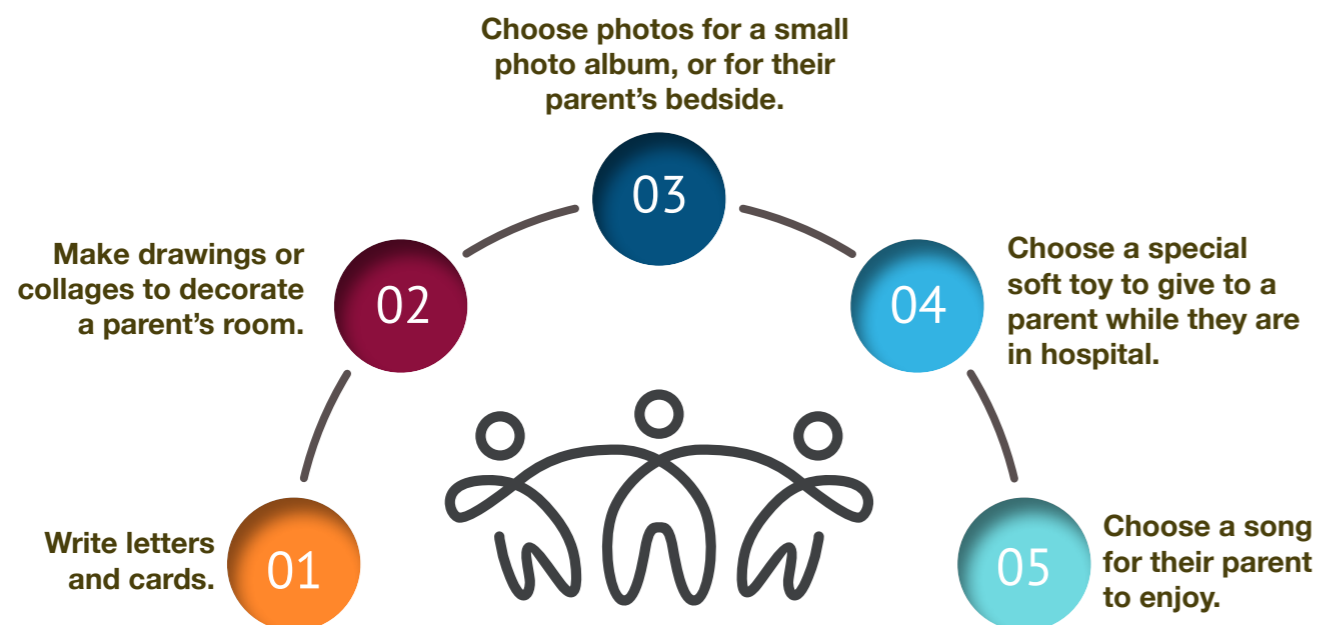
Everyone’s circumstances are unique, and we hope that this information can be adapted to your family or the family you are working with to benefit children.

There are suggestions for maintaining connections while a parent is in hospital, during rehabilitation, in transition services, returning home or living independently.

Support connections with a parent in hospital

Encourage children to be involved while their parent is in hospital. Wherever possible children should be given the opportunity to visit, while not being forced to if they do not feel ready. Some hospitals do not allow children under a certain age to visit Intensive Care Units so find out before planning a visit.

If a child needs more time before visiting the hospital they can be encouraged to stay connected in other ways, such as



While some children will be content being told about their parent's care and progress, other children will want to see for themselves.

“Every time he goes to hospital I want to visit him because he’s my Dad and I love him and I want to know if he’s alright.”

- Child



Some ideas for helping the visit go well

Check with staff that it is appropriate for the child to go in, as the situation may have changed.

Try to maintain a calm manner to help with reassuring the child.

Encourage the child to talk to their parent even if their parent is unconscious. Check with staff if the child can hold their parent's hand.

Limit the initial visit to 5-15 minutes, depending on the child. This will ease them into the situation, as spending too much time in an Intensive Care Unit can be overwhelming for anyone. If a parent or partner needs to be at the hospital for a long time, try to make alternative arrangements for children, as extended exposure to hospitals can be frightening and overwhelming.

Match visits to stages of recovery

Although each person with a brain injury is unique, there are some familiar patterns of recovery. In the initial stages, patients may be minimally or not responsive. During this time, visits need to be calm.

Many people recovering from brain injury go through a period of being confused and agitated, and during this time patients can become violent or abusive. Children need to be protected from visiting a parent in this state.

- **Reassure children that their parent's distress is a stage rather than a 'forever state'. For younger children you could explain that Mum or Dad is like a cranky bear waking after a long sleep.**

As parents continue to recover in hospital they may need frequent rests during the visit.

- **Help children bring an activity that can be done quietly during the visit such as colouring or word sleuths, so there can be natural rests in communication.**
- **Explain to children about a parent's need for frequent rests to help with healing, so that this is not interpreted by the child as a lack of parental interest or love.**

Debrief after the visit. If a child has been distressed by a visit, offer another opportunity to visit a bit later. Ask if there is anything you can do to make the visit better next time.

Support connections during rehabilitation or during transitions

When a parent lives in a rehabilitation centre, transition centre, or independent living centre, each visit is an opportunity for a child to become more accustomed to changes. Visits can be thought of as steps in the child coming to terms with a parent's injury. This can be a focus for planning each visit and building up routines and activities that help feelings of connection and belonging.

After a visit, check-in with children about how the visiting is going – is it too much, is it too little? Is there a problem about visiting that you could solve together?

Visits can be improved by developing familiar routines and activities that parents and children can enjoy together. Parents with brain injuries may need help to structure these activities. Rehabilitation providers may be able to help develop strategies as part of a client's rehabilitation goals for positive family connections.

Find who you can talk with to help set up some positive engagement activities during visits. Suggestions include games, craft projects, baking, going to the park.

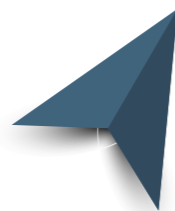
Support connections when a parent is not returning home

Sometimes a decision is made that a parent who has previously lived with children will not return to the family home. When a parent is not returning home, and parents are separating, many difficult decisions need to be made.

Strong and enduring relationships with parents can be fostered in all sorts of different caring arrangements.

Sources of support to help navigate children's matters in parental separation following brain injury

The rehabilitation service or disability provider can provide information about strengths and challenges the injured parent faces in terms of caring independently for children.



Mediation services, or family consultation services can help create a parenting plan that keeps the focus on what children need when parents separate.

Family therapists or psychologists can help families think through some of the issues involved.



Support connections when a parent's behaviour has changed

Each person with a brain injury is unique. Some changes in behaviour following brain injury can interfere with good relationship between parents and children. Here are some examples of changes and some suggestions for supporting children through these difficulties.

01

Challenge

As people recover they continue to be confused at times because of memory and thinking problems. For example, a parent with an injury might remember the main points in a conversation, but forget the details.

Ideas

Children can help by telling stories to their parent about events that have happened or are happening. This is a helpful task for children too, as it helps them practice putting together the puzzle pieces of memory to make sense of their experience.

Perhaps there is a game or activity that a parent used to enjoy with children pre-injury that can be enjoyed now as a way of connecting with children.

For example join the dots, colouring by numbers, snap, fish, dominos, etc.. Ask your rehabilitation service for suggestions.



“He remembers really big things, and things about me. But things like what happened last time I saw him, like that we saw a turtle in the park, I have to talk about it until he remembers.”

- Child



02

Challenge

Some people have **communication difficulties** after a brain injury. Without help to understand this, children can be left thinking a parent doesn't care or is not interested.

Ideas

Find out if a young person can attend a speech therapy sessions with their parent and learn how their parent's communication has been affected, and what are some ways they can make good contact.

Encourage children to speak simply and clearly.

Coach children to give their parent time to find the words and allow them to finish the sentence without jumping in to help.



“He knows that I have some troubles with talking (word finding difficulties), doing things, memories. But him and I, we like chatting, we are like friends. Because sometime when I’m talking I get blocked. He say, “Dad, it’s OK, calm down, I know, I know.”

- Parent



03

Challenge

As people recover, they often **are tired and continue to need breaks and rests.**

Ideas

Find ways to help parents and children notice when parents are becoming fatigued.

Support children to play alongside when an injured parent is too tired to participate.

Explain to children about the fatigue so they do not interpret it as a parent's lack of interest in them.



04

Challenge

Some people develop difficulties with controlling anger after brain injury. The parts of the brain that normally stop angry flare-ups have been damaged and do not do their jobs as well.

Ideas

Injured parents can talk with their rehabilitation team to get help to manage angry feelings that interfere with positive parenting.

Children can be helped to understand why someone with a brain injury might feel angry.

- **They may be mad because they cannot easily achieve things they used to do.**
- **Their feelings may be hurt because others treat them differently than before the injury.**

Children and young people's experience of a parent's uncontrolled anger following brain injury is distressing. Resolving this issue is very important for children's long term wellbeing.

Family Violence is never acceptable.

If aggression or violence is an issue, even if it is due to a brain injury, this needs to be dealt with. Everyone deserves to feel safe in their own home. The rehabilitation service or the disability service that provides support may be able to help with Positive Behaviour Support Plans, and a Safety Plan. SYNAPSE has information and advice to help families manage this situation.



Offer emotional support



Feelings unfold for children in response to the many ways in which a parent's brain injury can change a child's life.

It is normal for children to feel sad, angry or scared at times when they are faced with these changes.

Expressing feelings with words

Adults use words to express feelings more than children do. Often children (and adolescents!) do not talk about how they feel. They give one-word answers or say something like, "I miss playing with him" or, "I don't know". Children who are not talking about how they feel are **not necessarily "in denial" or holding it in.** There are lots of ways that children express themselves without words.

Help children talk about feelings.

An adult caregiver can help children talk about feelings by:

- Offering children time for their questions and feelings. Children may not take you up on this, but it lets them know you are available. Sometimes just knowing that there is someone to talk to helps calm emotions.
- Having regular talking times, such as during chores or car rides. Remember that children may express themselves in only two or three words and that is OK.
- Sharing your own feelings as a model for children.
- Find an opportunity for family therapy, or engaging the child in some counselling of their own.

Expressing feelings through art and play

Children express how they feel in their play. Through play children discover and experiment with their world. It is important for a child's development.

When younger and school-aged children experience a big change in their life and/or trauma, play can become their main way of expressing feelings. The best thing about play is that children love to do it.



Time-in with children

Children love to play anyway, but if you want to find a way to connect with a child during a difficult time, putting aside some time each day to play a game of their choice can help. For example, make it 10 minutes each day after dinner.



Self expression as children grow

Older children are not necessarily doing the creative play they used to. Some will talk about emotions but others can express themselves in different ways. Art forms can encourage self-expression, for example:

- Painting
- Drawing
- Clay
- Music (voice, instrument)
- Drama (e.g., making 'movies' at home)
- Writing

Letting young people know that you **appreciate, and want to nurture** their self-expression is just as **important to their development** as encouraging play for younger children. Let teens introduce you to their favourite music, YouTube clips or Tik-Tok challenges.



Practical ways to provide emotional support

Children respond to family crises in different ways. Some show strong emotions such as fear, anger, irritability or worry. Others might start behaving in ways that are a problem for parents and others such as being defiant, yelling or talking back. Some children have delayed reaction. They seem okay at first but then show emotions or behaviours later after the crisis has resolved.

Here are some ways you can help kids cope.

How to help

- Try to keep to normal routines as much as possible.
- If time is limited, safeguard some family time.
- Use consistent and clear rules and boundaries with predictable consequences for unacceptable behaviour. Give these calmly.
- Show warmth and appreciation.
- Include an activity that the child enjoys into their weekly routine such as sport, dance or drama.
- Think about how the child likes to spend time (time with you, getting to school early to play with friends, going to the playground after school) and find ways to include enough of these activities into each day or week.

A note about caretaking behaviour

Some children respond by trying to hide their own feelings, and look after others instead. While this might be a short term relief, it can have long term negative consequences for children who miss out on their childhood.

If your child is showing a lot of caretaking for others, then try...

- Encouraging the child to do age appropriate fun activities.
- Praising them for silliness and fun.
- Giving them defined roles for care-taking, so that they have a certain 'job' that is age-appropriate and know helps the family. Outside of this, they can do other activities.



If your child shares a worry, try to listen to what they are saying fully without dismissing it. If there is information you can provide to help or correct the basis of their worry, then do so, but do not offer false reassurances. Offering a hug, and saying "I'm glad you shared this with me" can be helpful.

Understanding children's distress

The process of treatment and rehabilitation following brain injury can mean a child lives with emotional strain for a long time.

Many people affected by brain injury experience noticeable changes in physical, cognitive and emotional functioning. These changes can affect children's relationships with parents and their emotional development. They may feel restless or unhappy because they do not know how to cope with the changes.

Children may mourn the loss of the way their parent was before the injury. If the injury was from an accident, they may feel the world is a more dangerous place since their parent's injury. If the brain injury was caused by an illness, they may become over-focused on any physical discomfort.

Children are in the process of developing coping strategies, and are usually focused on themselves and their own needs. They may begin to blame themselves for what they feel is going wrong in their family, not linking the difficulties with the adjustment to the brain injury.

For all these reasons children may be at risk of developing anxiety or depression. The following two pages provide suggestions about seeking professional help if you are worried about how children are coping.

Reach out for help if you are worried about how kids are coping

FAMILY THERAPY

Family therapy provides an opportunity for everyone in the family to talk about what is working well and what is difficult in the family. Family therapy can help come up with new ideas for dealing with the difficulties.

COUNSELLING IN THE NON-GOVERNMENT SECTOR

Many non-government agencies provide children's counselling services via a sliding scale of fees according to income. Some agencies also provide parent counselling and support. Some of the agencies that provide children's counselling services in Perth are Mercycare, Communicare, Anglicare, Wanslea and Relationships Australia.

YOUTH COUNSELLING

In acknowledgement of the increasing developmental pressures of adolescence, there are targeted services for this age group including Headspace and YMCA YCounselling (12-25 year olds)

COPMI (CHILDREN OF PARENT'S WITH A MENTAL ILLNESS)

Children's counselling can also be accessed through COPMI programmes that provide specialised support for children with a parent with a mental illness. Although these services will not be appropriate for all families, there will be some for whom they are appropriate and helpful. The Mental Health Commission of Western Australia fund COPMI programs.

COPMI services are provided by a number of agencies. Contact Arafmi WA, Wanslea, CLAN, MIFWA or Carers WA.

MENTAL HEALTH CARE PLANS

Your GP can also be a point of contact for accessing counselling for children. GPs can create a Mental Health Care Plan which provides a certain number of Medicare-subsidised sessions per calendar year with a private psychologist. There is usually a gap payment between the cost the private psychologist charges, and the rebate you get from Medicare.

Increase social support



Resources and practical support

A family may need help in ensuring that basic needs are met in the areas of work and finance, medical care, housing, education and child care after a parent has a brain injury.

- Ask to speak with the social worker at the hospital or rehabilitation centre
- Enquire about NDIS support
- Consider the **Wanslea Children and Parent Support Program (CPS)**

This is a home-based visiting program designed to build the capacity of families to care for their children during stressful times including parent illness.

Help children connect with community resources to provide social support and structured activities. Many of these issues may take some time to sort out.

- Sources of support for children can include
- **School**
 - **Local government**
Check out your local government services. Many local government agencies provide Kid's Clubs, Youth Group Activities, assistance with transport, libraries, gyms, and help to pay for costs associated with children's sporting activities.
 - **Counselling services**



Building resilience together

Focusing on building resilience is helpful for children long term. Resilience helps children thrive in tough situations. The experience children have within their family is one way of building resilience. (Other factors include the child's temperament, their experiences at school, and in their community).

Ways that families build children's resilience are:

- **Making sense and meaning from challenges**
- **Adapting to changes together**
- **Prioritising each other and closeness**
- **Talking through problems together.**

Having fun

Having a store of positive experiences and memories for children helps buffer the challenges that children face as they continue through life.

Family traditions promote a sense of belonging. The child has the feeling of belonging to a unique family in which they are a special and valued member. What traditions did the family have before the parent's injury, and are they still happening? Do the traditions need changing to adapt to the new situation? Are there others traditions the family could establish? Scheduling family traditions into the calendar each year can help family unity. Some examples include special holidays, birthday traditions, visiting family and summer holidays.

Family activities help children have fun in the family, promoting closeness and positive feelings. These provide regular predictable ways for families to enjoy each other and stay connected as children get older and lives get busier.

Adapting to change

We have described some of the changes children face when a parent has a brain injury. Here are some other changes that children may face.

Changes in the Relationship with a parent or carer who is not injured

Some children report that their relationships with their other parent or carer changes too. Caregivers may become overprotective in response to a traumatic event in the family resulting in children feeling frustrated. Other carers might rely more on children for support resulting in children feeling overburdened. The stress and worry experienced by an uninjured parent as they try to manage all the changes in the family can be interpreted by children as a parent not having time for them, or being cross with them.



Changes in the Relationship Between Parents

The relationship between parents changes after one member of the partnership has a brain injury. There may be more stressors and disagreement and these will result in changes to how children relate to parents. Keep arguments away from children and remember to tell children that disagreements are not their fault.

Changes in Friendships

Childhood friendships can be disrupted as children feel less connected to their peer group. They may feel that their friends are in a different 'space' to them, and that the usual concerns do not matter to them at the moment. They may feel that no one really understands what they are going through. They may not want to ask friends over any more as they may be embarrassed by the behaviour of their injured parent.

Talk with children about their friendships, and find out what is important for them. Consider talking with parents of children's close friends, and seeking their support for the friendship.

Advocate at school

Changes at home

A parent's brain injury may lead to changes in routines at home. Jobs that used to be done by one parent have to be covered in another way. Everyone might need to pitch in. Children are better with discrete jobs that have a beginning and an end, and can be learnt and repeated, such as taking the rubbish out, hanging the washing, emptying the dishwasher, cleaning the car. Expect to have to remind children to do these tasks or have a roster for them.

Helping kids manage changes

There is no quick fix or magic process to resolve these challenges. However, making time to talk continues to be important. Feeling respected and understood goes a long way towards finding solutions.

The overall approach that your family adopts to the injury is the most important message you send your children. Children will see in your words and actions that changes are recognised by you as symptoms of the injury, and they are no one's fault.

The way parents and caregivers use self-care and the support of family and friends is a model for children. They will benefit from all positive examples of coping.



Parenting is hard at any time, and parenting through a family trauma can feel overwhelming. What can help parents at this time?

Reach out to friends and family for support.

The following services provide parenting support:

- **Anglicare WA**
- **Meeralinga**
- **Ngala**
- **Communicare**
- **Relationships Australia**
- **Uniting WA**

Triple P parenting courses are currently free for all parents in WA through the WA Department of Education.

School is so important.

Children spend a lot of their awake life at school.

When a parent has had an injury or illness, school provides children with a needed sense of belonging to their community, normalcy, routine, and structure. In addition, education itself is provided at school.



But your child might find it hard to be as successful at school as they used to. This might be because...

- They do not have the same level of parental support in learning (e.g., practicing reading, times tables)
- They are distracted by worrying about the parent and not attending to their lessons
- They feel disengaged from their friends as now their challenges are shifting, and they feel 'different', or do not feel supported.
- They might get teased because of the parent's changes

Each child, family, and school is different.

You are this child's best advocate

Working with your child's school is crucial. Without discussion, the school will not know how children are affected, what to look out for, and/or develop a plan to help.

By talking with your child's school, you are not only helping, you are also being their advocate, and modelling for your child how to advocate for themselves.

Discussing the injury or diagnosis with your child's/ children's school

Parents often think about how to talk with their child's school about their own or a co-parent's brain injury or neurological diagnosis. This is a personal decision, and what works for your family and is in the best interests of your child might differ from what works for another family. Here we offer some ideas to think about and guidance that might be helpful in making this personal decision.

Who should I speak to?

You might think about:

Who spends the most time with my child?

Your child's teacher is most likely to be the person spending the most time with your child, and therefore would benefit from knowing about what could be affecting your child's behaviour and learning at school.

Who do I feel comfortable talking with?

There might be a central person, like a Deputy Headmaster, school nurse, or counsellor with whom you feel comfortable speaking. This person could serve as your contact person.

You could talk with more than one person,

depending on how your child's school is organised and what is in your child's best interests. For example, you could request a joint meeting with a teacher and school counsellor.

What should I say?

Knowing what information your child's school needs to support your child at school can be challenging to answer.

Some information you might like to consider discussing:

The parent's **diagnosis, and what that means for your child at school.** For example:

- You might have less time or ability to help your child with homework, even though you really value education.
- You might now need a stick to walk and your speech is slurred and you know your son/daughter is worried about being teased when you come to school.

Strategies you think could help keep your child on track with work outside the classroom, for example:

- The possibility of a homework club.
- For you and the teacher to have a school-home communication book in which the teacher records homework that can be easily checked.

If you cannot think of any strategies, maybe others at the school can.

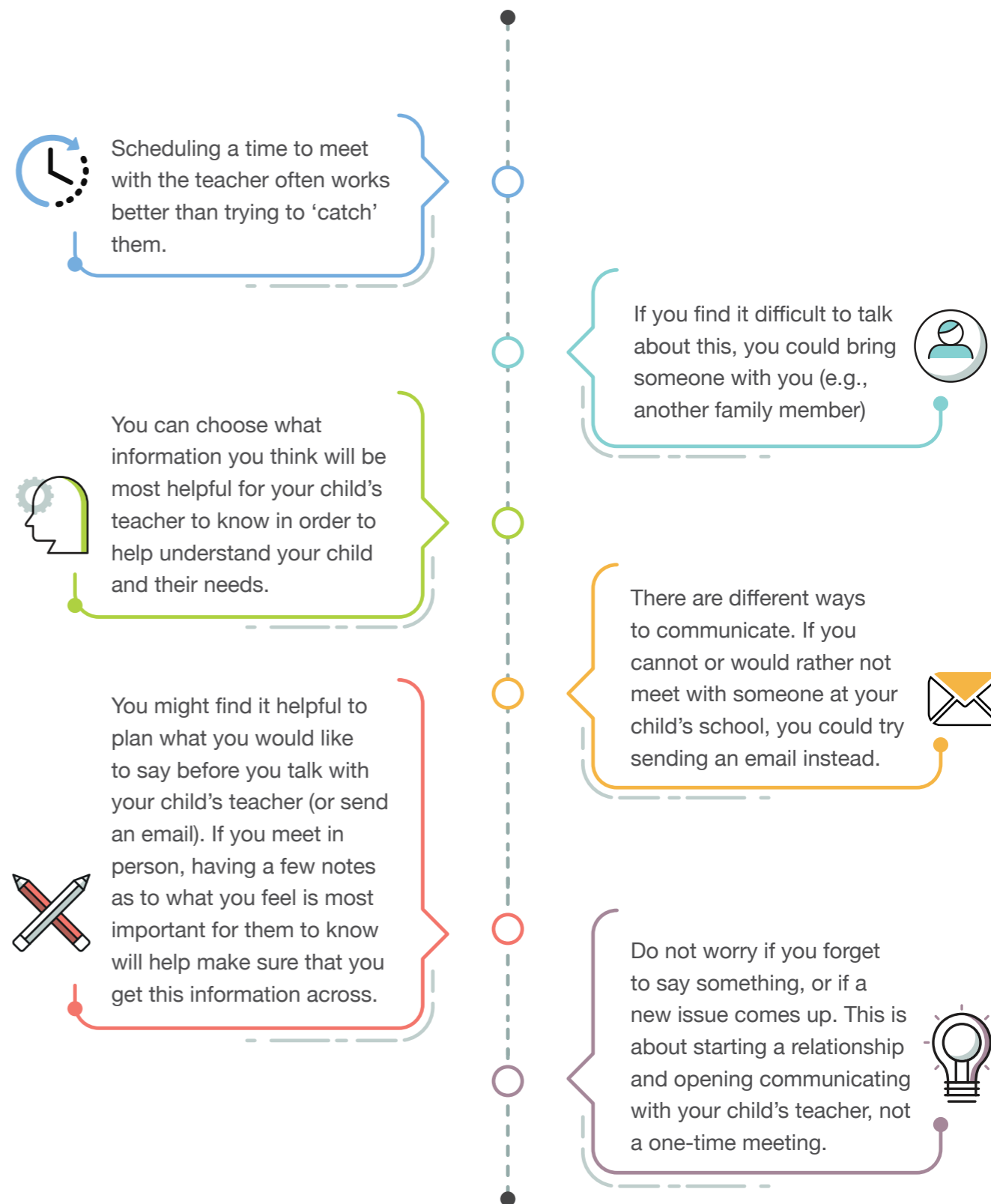
What you are hoping for your child at school. For example:

- Hope that your child learns that school and home are working as a team.
- Hope that your child experiences understanding, and that school is a safe place.

Express that you are **open to changing strategies,** and realise that new issues might arise. Let the teacher know how to get in contact with you, and ask how it is best to contact them.

On page 39, you will find a sheet with these ideas started that you might find helpful to fill out.

I know what I want to say... How might I go about saying this?





Developmental Considerations

Although this section has been designed for primary school-aged children, it can also be useful for other age ranges.

Infants, toddlers, and pre-schoolers: you do not yet have school to discuss these issues with, but you might still wish to talk with any other childcare providers. In this case, you might find some of this still helpful in guiding what you want to say.

Older children and adolescents: Older children and adolescents might not want to discuss these issues with you or their school, but would still benefit from this discussion. Think about teaching them to be advocates for their own needs, and modelling for them how to do this by involving them in some of these decisions and discussions. You could both try advocating together, or one at a time. For example, you might sit down with an adolescent and problem-solve who to talk to, and what is important to say. We have included a separate resource for parents who wish to involve their children in these decisions and/or discussions.



Should I mention this to my child?

Being honest with children is important in building a solid relationship. Depending on their age, they might not be involved in the discussion or the decision making process.

Letting the child know who you have spoken to about what, and why (e.g., what you are hoping to achieve for your child) not only builds honest communication, but also shows the child that you are their advocate.

Primary School: What I'd like to tell my child's school

You can fill this in if you think it would be useful for you to organise your thoughts. You can add, change, or delete any sections... different families will have different needs. If you have more than one child, you might also like to make a different sheet for each.

01 The **brain injury and what that means for my child at school.** You might include a) how the injury impacts on the parent, and b) how the injury affects your child at school.

02 **Strategies that you have found helpful, or might find helpful.** You might have some ideas as to what would work for you and your child (such as introducing the school counsellor and opening the door to communication; a homework club; emailed reminders for forms), or you might not have any, in which case you could suggest trying to brainstorm ideas. If you are open to new ideas, then you might add this so that the teacher knows.

03 **What you are hoping for your child at school.** What are you hoping to achieve in sharing this with the school? Are there any particular goals or hopes that you have for your child at school?

04 Express that strategies might need to change, and new issues might arise. Advise the teacher **how it is best to get in contact with you, and ask how it is best to contact them.**

Middle & High School: What we'd like to tell the school

You can fill this in if you think it would be useful for you to organise your thoughts. You can add, change, or delete any sections... different families will have different needs. Many heads are better than one – so try involving both caregivers and children/adolescents in completing this.

01 The **brain injury and what that means for me at school.** You might include a) how the injury or illness impacts on the parent, and b) how the injury or illness affects you at school.

02 **Strategies that you have found helpful, or might find helpful.** Depending on how the parent's brain injury impacts on you at school, you might have some ideas as to what would work to support you (e.g., speaking with a school counsellor, access to a homework club). If you do not have any, in which case you could suggest trying to brainstorm ideas. If you are open to new ideas, then you might add this so that the teacher/school knows.

03 **What you are hoping for at school.** What are you hoping to achieve in sharing this with the school? Are there any particular goals or hopes that you have for this school year or term?

04 Express that strategies might need to change, and new issues might arise. Offer the teacher **how it is best to get in contact with you, and ask how it is best to contact them.**

This material is based on:
Ohan, J. L., Eaton, K., & Corrigan, P. W. (2016). *Starting the Conversation: Do you want to talk about your child?* [Unpublished therapy manual, based on the Honest, Open, Proud Program]. School of Psychological Sciences, University of Western Australia.



Strategies: School-home communication book

It can be hard to stay in touch with your child's school. Sometimes this means that you feel like you are out of touch as a caregiver. Staying involved means that you can pick up on issues before they get bigger, and feel more connected.

One way to achieve this can be a school-home communication book. This asks teachers to do a quick daily (or weekly) report or what is going on for your child. It can include different topics according to what you need. We suggest:

- What homework is there?
- Were there any issues – positive or negative – that arose today?

In turn, you can report any issues from home for school the next day (or week).

You might find this to be a helpful strategy to support your child's success at school.

On the next page you will find a suggestion. You can change it to suit your child, teacher, and school.

The biggest tip... **keep it simple!** What do you really need to know, and how can you do that quickly?

As your child develops, they can learn to take the role of being the communicator. This can be modified for adolescents, who can start to be in charge of their own book.

Primary School Aged Children

Rules and fairness are very important to primary school children. Children expect the world to be fair, and they react with distress when situations seem unfair. A brain injury is not fair, and the process of recovery does not follow rules. Adult caregivers who can acknowledge what is unfair, disappointing or difficult help children cope. Let children vent their disappointments and then turn the conversation to what is possible. Be creative about second-best plans (Read, ‘The Get Around’).

After a parent’s injury children might suffer from more illnesses and aches and pains. Their sleep or appetite may be disturbed and their concentration and activity levels may be reduced.

Work with the school to manage a child’s workload during very difficult times, and then get support from the school to help your child catch up.

Look for opportunities to counter any worries a child may have that they caused the brain injury or that they are making it worse in some way. Remind children that brain injury is rare, and that their other caregivers are well.

Encourage sports and active play in order to lessen a child’s anxiety and physical tension. Encourage art, music, dance, singing, crafts and other expressive processes. Support children to make gifts or contribute in ways to help their parent.

Adolescents

A major developmental task for teens is the establishment of their own identity. This frequently causes conflicts in relationships with parents. Adolescents might feel conflicted about pursuing their own goals, when they know they are needed to help out at home. Continuing with activities outside the family, such as sports, hobbies, study or travel plans helps adolescents manage worries and sadness about their parent. Fulfilling responsibilities in the family can help adolescents develop a sense of positive identity. However running parallel can be feelings of resentment about increased responsibilities at home. Adolescents want to be treated like adults at times but they still need adult advice and help.

Contact with other young people in similar situations is very important. Contact Synapse family and carer support.

A family crisis can help adolescents become determined to create a life for themselves that their parents could be proud of.

For Children

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Brain Injury Association of Maryland. (1995). *Why did it have to happen on a school day? My family’s experience with brain injury*. Brain Injury Association Inc.

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Headway Ireland (2016). *A kid’s guide to brain injury*.

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Resources

For Adolescents and Young Adults

Cotter, D., Lopez, L., Kelleher, E., Coughlan, H., & Cannon, M. (2016). *Journey through the brain: A colouring book*. Royal College of Surgeons Ireland.

Headway Ireland (2016). *A teen’s guide to brain injury*.

Headway Ireland. (2019). *The brain and brain injury*. <https://headway.ie/wp-content/uploads/2016/11/The-Brain-and-Brain-Injury.pdf>

McCaffrey, K. (2014). *Crashing down*. Fremantle Press

For Adults

Ahmad, T., & Johnson, J. (2016). *Supporting children when a parent has had a brain injury*. Headway UK.

Clark-Wilson, J., & Holloway, M. (2019). *Family experience of brain injury: Surviving, coping, adjusting*. Routledge.

Useful Websites

Acquired Brain Injury Outreach Service (ABIOS)
<http://www.health.qld.gov.au/abios/>

Brain Injury Explanation
<https://www.braininjury-explanation.com/>

Brainline interactive brain
<https://www.brainline.org/tbi-basics/interactive-brain>

Center for the Study of Traumatic Stress
https://www.courage2talk.org/documents/1_Fam_R4R_Communications_children.pdf

Dementia Australia: The Brain
<https://dementiainmyfamily.org.au/age-5-8/the-brain/>

Headway Ireland
<https://headway.ie/>

Headway United Kingdom
<https://www.headway.org.uk/>

SYNAPSE
<https://synapse.org.au/>

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📧 research.enquiries@brightwatergroup.com

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Brightwater

Brightwater Care Group

2A Walter Road West
Inglewood WA 6052

W brightwatergroup.com/research/
E research.enquiries@brightwatergroup.com

ABN 23 445 460 050 ACN 612 921 632