Headway
the brain injury association

Supporting children

when a parent has had a brain injury

This publication has been written to offer information and advice on how to support a child when their parent has had a brain injury.

This publication is also available as a printed booklet, which can be purchased from our online shop.

www.headway.org.uk
0808 800 2244

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Introduction

When a brain injury happens, adults may instinctively want to protect children by not talking about what has happened. However, if the injured person is a close relative, such as a parent, the child will need to know a few basic details.

Research suggests that children cope much better if they are told the truth and kept informed at a level that makes sense to them. This is especially important in the early days when a parent is first admitted into hospital, as the child will wonder what has happened to their parent and will probably experience a disruption in their normal routine. They will also likely

continue to need support when the parent comes back home, although how much will depend on the parent's own support needs, effects of the injury and the child's temperament.

This publication has been written to offer information and advice on how to support a child when their parent has had a brain injury. Information and support for the brain injured parent themselves is available in our publication *Parenting after brain injury*.

The information in this publication does not replace clinical guidance from medical professionals. You should always get advice from your GP or other suitably qualified professional for help with managing the effects of brain injury.

Children's reactions when a parent is in hospital

The way a child responds to their parent sustaining a brain injury will depend on a number of things – their attachment to the parent, age and level of maturity are key factors in their response. Here is an overview of some common responses that different age groups of children may have to their parent being in hospital with a brain injury.

Babies and toddlers (0 – 3 years old)

Very young infants such as babies and toddlers are not yet able to comprehend what is going on around them and do not have the verbal skills to articulate how they are feeling. However, this does not mean that they are not sensitive to changes in the environment, particularly stressful changes such as if a parent is away in hospital. They may show uncharacteristic behaviours

such as excessive crying, trouble with sleeping or feeding issues, and it may be harder than normal to settle them.

You can support infants that are demonstrating this kind of behaviour by spending more time with them and offering as much physical comfort as possible. Try, if possible, to maintain the routine that the child had before their parent went into hospital, such as keeping feeding and sleeping times the same. This can help to maintain as much stability in the child's life as possible.

You yourself may need to take time away to visit the parent in hospital, and it may not be possible to bring the child along with you. If this is the case, try to arrange for other close relatives or family friends to stay and look after the child rather than using unfamiliar babysitters.

Young children (3 – 8 years old)

Children of a young age may be upset or appear concerned for a short while, but they will probably revert back to their normal activities quite quickly. If they ask questions these will normally be quite direct and may focus on themselves, such as 'who will take me to school?'

Young children often have a short attention span, so if they do ask about their parent keep any information that you share with them basic and simple. For example, 'Daddy hurt his head and had to go to the hospital. He is feeling very poorly, so the doctors and nurses are looking after him.'

You or others may notice changes in their behaviour, and they may revert to habits previously outgrown, such as thumb-sucking and bedwetting. They may become more demanding of attention, misbehave or alternatively become withdrawn.

Children often act out their feelings through play or drawing. This can help them to make sense of their feelings and the changes that have happened, especially if you keep talking to them about what they are doing. However, speak to your GP about a referral for professional help if their activities or conversations begin to show signs of constant anger or take on a morbid theme, or if their talk or behaviour becomes abnormal.

Older children (8 – 12 years old)

Older children are more likely to want more information, and will question what they are told. Information should be more detailed than for a young child, but still basic enough for the child to understand, such as '*Mum had an accident today – she banged her head quite badly, and she has gone into hospital. She is 'unconscious' and looks like she is asleep but she is like this because her brain is damaged and it can't do what it should be doing. The doctors are working really hard to help her*.' Avoid telling children that their parent is actually 'asleep', as children may become fearful about falling asleep or not waking up, especially if the parent dies.

It is possible that the child may ask if their parent is going to die. How you approach this will of course depend on how much information the hospital have been able to give you. It will also depend on the age and personality of the child. While it can be beneficial to hold back some details, especially if you are unsure of a prognosis, it is paramount that your responses are honest. It is also fine to admit that you don't know, for example, '*Mum is really poorly. We don't know what will happen over the next few days but the doctors and nurses will do everything they can to help her. They will tell us if Mum starts to get better*.'

Children of this age (and above) may benefit from writing their feelings down. They may feel uncomfortable discussing their fears out loud, so writing them down means that they don't

have to openly discuss their feelings whilst still safely expressing themselves. They may want to share what they have written or they may wish to keep it to themselves. Either way, a notebook can provide a useful outlet for their emotions.

Teenagers and young adults (12+ years old)

At this age, most children will have more understanding and knowledge of serious illnesses. It is likely that you will still wish to protect them, but they may make their own assumptions if they feel information is being withheld. In this situation, after giving basic details of what has happened, allow the child to guide the conversation further. Reassure them that you will tell them what you know, and that you will be honest. They may be reluctant to ask you questions for fear of up-setting you, as children of this age usually have the ability to understand how someone else is feeling (empathy).

However, if they are given time and allowed to come back to the conversation at a later point, they may feel confident in asking more searching questions. Some children will feel more comfortable talking to a relative or someone outside of the immediate family. If this is the case, ensure that the person concerned has the latest information, is aware of anything you don't want the child to know, and understands their personality.

Teenagers and young adults are already going through a challenging period of their life, and so it is important that they are able to spend time alone or with their peers. However, it is also important for them to spend some time alone with you, even if it is just a few quiet minutes at the end of the day.

Online communities and social media are often popular with teenagers and young adults, and they may find it easier to share their thoughts online than through talking in person. Encourage teenagers to make use of our online

communities, where they can safely share their feelings with others who have been affected by brain injury.

Visiting a parent in hospital

Some hospitals do not allow children under a certain age to visit Intensive Care Units, so you should always check this with the unit before speaking with the child about visiting. If the child is allowed to visit and you are considering taking them to see their parent, the following points may be useful.

Making the decision to visit

- Has the child actually expressed any thoughts about visiting? If so, have they asked to go or stated that they do not want to? At this stage, anything the child says that demonstrates their wishes or fears should be taken into account when making a decision.

- Prior to arranging a visit, ensure that the child understands and accepts the information that they have been told so far. You may have to repeat the information on several occasions to ensure that they properly understand and are confident in their decision about visiting.

Preparing for the visit

- Speak to the staff on the unit in advance to ask for their help or input when the child visits. There may be staff that are trained to help children through their first visit, and they may be able to suggest a time when the unit is calmer than usual.

- Speak to the child's teacher at school so that they are aware of the circumstances and can help if needed.

- Explain what the unit is like to the child so that they are prepared for the sight of machines and lots of noise.

- If the parent has any physical injuries such as swelling, scars or tubes attached to them, discuss this with your child first to help reduce shock or fear.

- Consider showing the child a photograph of their parent in hospital to prepare them for how their parent may look.

- Agree on a 'code word' with the child in advance; this code word can then be used during the visit if at any point the child wishes to leave.

- Reassure the child that they can change their mind at any time. If they get to the hospital and change their mind, allow them to wait for a while. They may or may not decide to go in, but either way, support them with their decision.

Visiting the parent

- Before entering the unit, ask to speak to a member of staff on your own. Seek an update on the parent's condition so that this does not need to be done in front of the child. You should also check with staff that it is still appropriate for the child to go in, as the situation may have changed since you last spoke with them.

- Try to maintain a calm manner to help with reassuring the child. They will need to feel a sense of security around them, and if they are made aware of your anxiety they may become

more fearful.

- Take a trusted friend or relative to support you. They can also sit with the child in the waiting area if needed, such as if you want some time alone at the parent's bed-side or if the child is uncomfortable in the unit. If this is not possible, ask for a member of staff to help you.

- Encourage the child to talk to their parent, and after checking with staff suggest that they hold their parent's hand. This can comfort the child and can also be useful as part of a coma stimulation programme (for more information, see our publication *Coma after brain injury*).

- If the child becomes upset and can't be comforted with gentle reassurance, allow them to leave the unit for either a 'short break' or to visit another time.

- 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 Intensive Care can be overwhelming for anyone, especially during a first visit.

- Reassure the child frequently and allow them to ask questions.

After the visit

- Allow time for questions, but if the child does not wish to talk immediately after the visit, offer a change of subject or just some quiet time for them to think things through. They may come back to talk later.

- Be prepared for their distress – this may not be immediate and may be expressed in various forms. For example, they

may become upset about something at school that would not usually affect them. Again, calm reassurance, spending time together and allowing the child to talk can help to ease their fears.

- The child's distress will naturally upset you. Try to ensure that you have support around you and don't be afraid to ask for help yourself. For more information on accessing support at the hospital stage, see our publication *Hospital treatment and early recovery after brain injury*.

Dos and don'ts

Dos

- Try to maintain a routine at home, such as the child's usual school run, meal-times and after-school activities. Enlist family and friends to help out where they can.

- Inform schools of the situation and keep them updated. Teachers can be asked to stay vigilant for changes in behaviour or difficulties with completing homework and offer support accordingly. Some schools have mentors or counsellors who are trained to help children going through distressing times.

- Suggest that the child make a card, write a letter or record a message for their parent. They could take this to the hospital if they are visiting or you could take it for them. This will help them to feel that they are communicating with their parent and being useful.

- If the child shows anxiety when you are leaving them (such as if you are visiting the hospital without them), reassure them that you will return and give them a realistic time to

expect you back by. If you are held up, try to let them know beforehand so that they do not worry, and give a new time for when you will be back. Children of any age can become afraid that, because something bad has happened, it will happen again, and they may worry for your wellbeing.

- Allow time for the child to talk about other things that may be bothering them, such as homework or problems with friends. It may be difficult to give them your full attention, but allowing them to talk will benefit them as their usual routines continue.

- Always try and answer questions honestly, however trivial they may seem, and be honest even if it means admitting you don't know.

Don'ts

- Avoid making false promises such as when exactly their parent will be home. The child needs to know that they can rely on what they are being told.

- Don't be frightened to show your feelings – children often hide their fears because they do not want to upset anyone. Never assume that because a child is not expressing how they are feeling, they are not affected by the circumstances. Perhaps they are waiting to see an adult's response to get 'permission' for expressing themselves as well.

- Avoid having 'adult' conversations within the child's hearing range. They may only understand some of it, but this could be enough to trigger new fears.

- Try not to rely too heavily on older children. They may want to help and take on some responsibility to help you, but they

may grow to resent it over time. Instead, encourage all the family to work together to make home life a little easier. Younger children could tidy up their own toys, get ready for bed by themselves or put their rubbish in the bin. Older children could read a bed time story to their younger siblings, or if they offer to help, suggest something they could do on occasion rather than every day, and offer frequent acknowledgement and praise for helping out.

- Try to avoid telling the child not to be sad or not to worry. These are natural emotions and children should not be made to feel as though they need to hide their feelings. At the same time, reassure them that it is okay to laugh and have fun – they are not being disloyal or insensitive to anyone's feelings by doing so.

- Try not to get into arguments with teenagers who express frustration or anger, or who spend more time out of the house with their friends. It is quite normal for teenagers to have mood swings, and the additional stress of having a relative in hospital can exacerbate this. If the teenager becomes resistant and withdrawn, try to encourage another member of the family to speak with them, or encourage them to talk to their friends.

When a parent comes home

Having a brain injured parent return home from hospital can bring mixed feelings for children. This can depend on how long the parent has been in hospital, and how much information the child has been given in the meantime.

Some children may feel apprehensive about seeing the parent again if they know that the parent's injury was serious (or if the parent is 'very poorly'), or if the parent has been away from

home for a long time. They may find it difficult to readjust to life again, and may be distant when the parent first returns home, especially if the parent is experiencing cognitive, emotional or behavioural effects from their injury.

Many children will be relieved and overjoyed to have their parent back home, and unless there is an apparent physical change they might think that life will go on as normal. It is important to prepare the child by giving them a brief overview of how their parent might be different when they return home. You yourself may not actually know this yet, especially as many effects of brain injury are not obvious until days, weeks or even months after a person leaves hospital.

However, it is still important to let the child know that their parent might be different in some ways and they will probably need a lot of rest when they come home, especially during the first few weeks of being back.

How well children are able to adjust to the change in circumstances will depend on their age and the effects of brain injury that the parent is experiencing. Here is a list of some of the common changes after brain injury and how children may respond to them.

Physical changes

Common physical changes after brain injury include mobility and co-ordination problems, weakness or paralysis, fatigue, pain, difficulties with speech, hormonal imbalances, epilepsy and spasticity.

Young children

Children of a young age may find it easier to understand that their parent has had an injury if they can see a physical change; this might include things such as

mobility issues or difficulties with speech. Other physical issues such as headaches or sensitivity to loud noises might be more difficult for children to understand, although they are sensations that the child might still be able to relate to if simple language is used, such as ‘daddy’s head hurts’ or ‘mummy does not like loud noises’. Young children may be apprehensive or fearful if they see physical changes, and they may be particularly sensitive to any facial injuries that the parent has.

Older children

Older children may understand ‘hidden’ physical effects such as pain, headaches or fatigue better than younger children. They may be asked to help around the house more, or they may be required to provide physical support to the parent. As older children are often more independent they may not feel upset if the parent is no longer able to do physical activities with them; however, they may spend more of their time helping to look after the parent and in doing so become a young carer. Further information on this is available in the section ‘Young carers’.

Emotional and behavioural changes

Common emotional and behavioural changes after brain injury include mood swings, exaggerated emotions, personality change, depression, anxiety, anger and loss of inhibition.

Young children

Children of all ages, even babies and toddlers, respond to simple emotions such as happiness, anger and sadness. For instance, very young children may cry in response to extreme emotional outbursts, such as anger. The ability to understand how someone else is feeling (a skill called empathy) starts to develop at around the age of 3. At this point, children may feel sad, worried or fearful of any emotional changes the parent

has, and may blame themselves for this. Reassurance and simple language can be used to help the child understand that their parent's behaviour is no one's fault and the parent is not feeling angry or sad because of them, for example 'Mummy is not angry at you, she is having a poorly moment.'

Older children

Older children will have more of an understanding about emotions and may respond directly to emotional changes in a parent. They may reciprocate happiness or sadness, or shout back if the parent gets angry. It might help the child if you share some anger managing techniques with them in simplified language. As older children are more sensitive to emotions, their parent's emotional changes might have an impact on their own personal emotional wellbeing. It is therefore important to ask the child how they are coping on a regular basis, and to find out if they need any support.

Cognitive changes

Common cognitive changes after brain injury include problems with memory, language, attention and concentration, and a range of skills that are collectively known as the 'executive function'.

Young children

Cognitive changes are often the most difficult effects of brain injury for children to understand as they are often 'hidden'. They may only understand the cognitive effect when it has a direct impact on their own lives, such as if the parent forgets a birthday due to memory problems, or can no longer play with the child whilst cleaning because they can no longer multitask. Again, reassurance and simple language can help the child to

understand that the behaviour is not intentional. If possible, try to find children's movies or books featuring characters that have problems with skills such as memory, as this might make it easier for the child to understand.

Older children

Older children will probably be able to better understand cognitive changes in a parent, although the term 'thinking skills' might be easier for them to understand than 'cognitive skills'. They may also find it simpler to understand if relevant examples are given, such as 'dad finds it really hard to concentrate, so he can only help with your homework for 10 minutes.' Children of an older age might benefit from being taught basic information about the brain to help them with understanding how physical injury to the brain results in cognitive problems.

There are plenty of children's textbooks that have been written about the brain which might be useful for children of this age.

Young carers

Sometimes children in the family are required to take on additional caring responsibilities to help their disabled parent around the house. This might include physically helping to care for the parent, or taking on additional jobs in place of the parent such as grocery shopping or looking after younger siblings. Many children will also become a main source of emotional support for the parent, who may either have emotional effects as a direct result of injury to the brain, or be struggling with the changes in life that the injury has brought. Seeing a parent emotionally distressed can be difficult enough for a child, and this might be harder if they are required to provide emotional support to help the parent.

Taking on these additional responsibilities may lead to the child having less time to socialise and enjoy the activities that they did prior to the parent's injuries. This can result in feelings of being left out from their peers. Young carers may also struggle with things such as completing homework or engaging in after-school activities. As a result, their self esteem or sense of self worth might be affected, especially as peers have a large role to play in children developing a sense of self identity.

Children will not always speak up when they are having such difficulties, and they may start to experience problems at school if teachers are not aware of their caring role. They may feel as though they are not allowed to talk about their home life, and that doing so will seem as though they are complaining. It is therefore important to ensure that if there are young carers in the family, they are given the chance to regularly speak about how they are feeling with someone they trust, and are encouraged to seek support if they are struggling with their caring role.

Support can be accessed from the following carer's organisations and schemes.

The organisations listed below are provided for information purposes only. Their inclusion does not imply endorsement, recommendation, or approval by Headway. Users should make their own assessment of any organisation or service before engaging with them.

- Carer's Trust: www.carers.org
- Carer's UK: www.carersuk.org
- Action for Children: www.actionforchildren.org.uk
- Carer's Federation: www.carersfederation.co.uk
- Carer's Direct helpline: 0300 123 1053
- Barnardo's: www.barnardos.org.uk
- The Children's Society: www.childrenssociety.org.uk

Some council authorities will also have local services for young carers.

Other suggestions

Below are a number of other general suggestions that can help with supporting children when their parent has had a brain injury:

- Encourage the child to talk to their parent about how they feel. Communication is an important part of any relationship especially between a child and a parent. If the parent struggles with concentrating on conversations, or remembering them, encourage the child to write letters or notes that the parent can read in their own time.

- Try to encourage the parent and child to find new activities to do together if the parent is no longer able to do things that they enjoyed before the injury. This can even be simple activities such as taking a walk, watching television or listening to music together.

- Be aware of any signs of bullying that the child may be experiencing at school because their parent is ‘different’. If you do suspect bullying, have an open conversation with the child and inform the school.

- If there is a specific change to the child’s routine, create age appropriate pictures, posters or diagrams of the new routine for the child to refer to. A visual guide such as this might help the child to remember, adapt to and accept changes.

- Acknowledge and reward children for helping out with their parent. For example, you could give stickers to a young child every time they have been quiet when the parent is fatigued.

Older children can be given other types of rewards such as more time playing computer games or spending longer with their friends whenever they help out around the house.

- Encourage children to learn about the brain using interactive websites and textbooks.

Conclusion

Children will have different responses to a parent being in hospital with a brain injury, depending on factors such as their age, level of understanding and personality. Feelings of sadness, fear, restlessness or anger are all common emotions for children to have during such a time, and it can help to provide constant reassurance and offer regular opportunities to talk about how they are feeling. There may be changes in the routine once the parent returns home and children may find it difficult to readjust to this. However, with the right kind of understanding and support, this can be made easier for the child.

The way a child copes in a difficult situation can in part depend on how the adults around them are coping. If you are a main carer of the child whilst the parent is in hospital, you should make sure that you are accessing support as well. Delegate responsibilities to other family members if you can, and don't be afraid to ask questions and get support from appropriate hospital staff.

Our nurse-led helpline is also available to offer information and support, including how to look after yourself, on 0808 800 2244 or helpline@headway.org.uk.

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We hope that this has been a helpful resource. Please consider sharing your feedback with us by scanning the QR code or by visiting our publication feedback survey https://uk.surveymonkey.com/r/hwpublications.

Learn more and support our work at www.headway.org.uk/get-involved.

This information was last reviewed in 2016.

We're here to listen.

If you need support, or have a question about brain injury, contact our free nurse-led helpline:

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