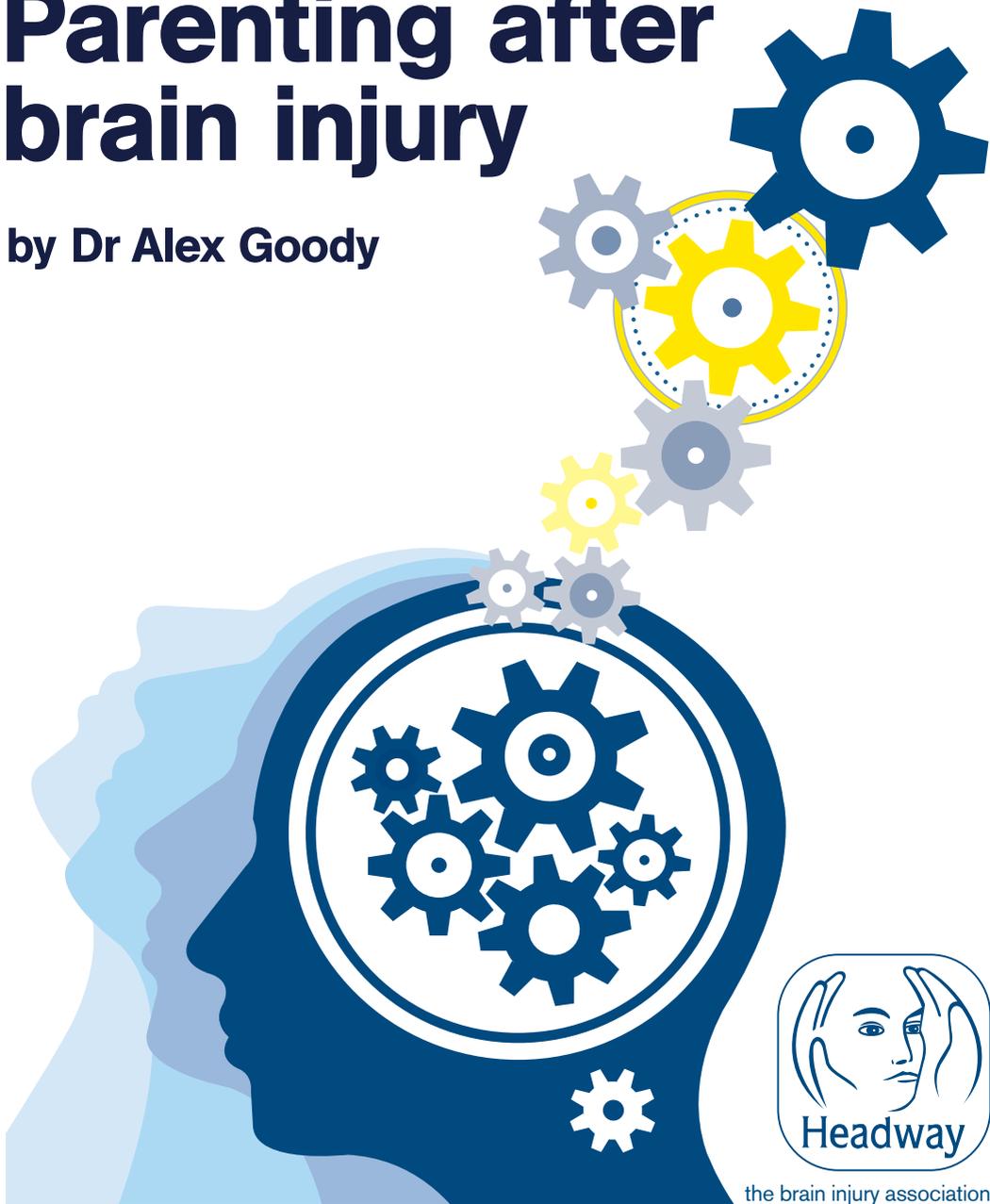


Parenting after brain injury

by Dr Alex Goody



the brain injury association

This booklet has been written to help those parents who have had a brain injury understand how their injury has affected them in their role as a parent.

■ Parenting after brain injury

This e-booklet is an adaptation, created in August 2017, of the Headway print booklet *Parenting after brain injury* and may contain minor updates to the original version.

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Headway – the brain injury association
Bradbury House
190 Bagnall Road
Old Basford
Nottingham NG6 8SF

Author: Dr Alex Goody, Consultant Neuropsychologist, Walkergate Park Centre for Neurorehabilitation and Neuropsychiatry, Newcastle.

Edited by Tamsin Ahmad - Publications and Research Manager, Headway - the brain injury association, Nottingham. Previously edited by Esme Worthington.

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Introduction



A brain injury can happen to anyone at any time, and this includes significant numbers of people who have children. After the initial trauma, much of the emphasis of rehabilitation is on helping the person themselves to recover – perhaps learning to walk or talk again, or finding ways to overcome memory problems or fatigue. However, the person with a brain injury will at some point return home to being a parent, whether or not they feel they have recovered sufficiently.

People with brain injuries often report that not only has their ability to carry out parenting roles been affected by their injury, but also their relationship with their children has changed. Sometimes it is the changes in relationships that people find hardest to adjust to, even more so than the practical changes which may be necessary.

This booklet is designed to help those parents who have had a brain injury understand how their injury has affected them in their role as a parent. There are also practical strategies and advice to help deal with these changes, in particular rebuilding relationships with children.

Why might parenting change after traumatic brain injury?

Broadly, there are two main reasons why parenting may change:

- 1 The person may have **cognitive (thinking)**, **physical**, **emotional** or **behavioural** changes as a direct result of their injury which affects their ability to parent.
- 2 Often after a brain injury much of the pattern of family life is disrupted or changed. For example, the person may no longer be able to work, or they may require care from family or paid carers. It is also important to recognise that children change too, particularly if there were traumatic circumstances to the injury, or if the parent has spent a long time in hospital. Sometimes then, parenting changes because the relationship between the head injured person and their child, or children, has changed.

Which features of brain injury may impact on parenting?

Cognitive (thinking) problems	
Long-term memory problems:	<ul style="list-style-type: none"> ● Forgetting the details of important events in a child's life such as their birth or early years. This leads people to think they cannot remember, or do not know their children well. This affects the bond that the parent feels for the child (and vice versa).
Everyday memory problems:	<ul style="list-style-type: none"> ● Not being able to remember a route around town, or getting lost while taking children to school. ● Forgetting to give children dinner money, or to remind them to take the correct kit to school.
Attention:	<ul style="list-style-type: none"> ● Finding it difficult to follow a conversation when more than one person is talking at a time. ● Not coping well with the noise and extra demands when a child brings friends home from school.
Language skills:	<ul style="list-style-type: none"> ● Difficulties with reading, writing or spelling, which make helping children with their homework difficult.

Planning, judgement and insight:	<ul style="list-style-type: none">● Not being able to express thoughts or feelings in the way that you might want to, especially when disciplining a child.● Not supervising small children properly. Leaving children to their own devices to play, when it is not really safe to do so.● Getting carried away playing 'fun fights' with children, and not realising that the game is becoming too rough.● Taking children out for the day to the seaside, but not thinking ahead to take dry clothes, towels and food supplies.
Behavioural problems	
Irritability and temper:	<ul style="list-style-type: none">● Becoming annoyed with children too quickly if they are noisy or badly behaved.
Impulsivity:	<ul style="list-style-type: none">● Changing a decision that is important to the child, without offering an explanation.
Emotional problems	
Depression or low mood:	<ul style="list-style-type: none">● Believing that he or she is no good as a parent and withdrawing from contact with the children, leaving it all to the other parent.

Emotional problems

Anxious or
obsessional
concerns:

- Not wanting to face other people (e.g. avoiding the playground where other parents are around).
- Worrying about children's safety (e.g. always worrying that they may die in an accident).
- Wanting the house to be immaculately tidy and finding it hard to tolerate children's toys left lying around.

Physical problems

Mobility:

- Being unable to run and play with the children, (e.g. playing football in the park).

Co-ordination:

- Being unable to help small children fasten buttons or tie shoelaces.

Fatigue:

- Feeling too tired to take the children on trips or out shopping, perhaps becoming very tired after only half an hour or so.

Social and practical problems

Driving:

- Being unable to drive, so always relying on others to help transport the children.

Epilepsy:

- Not being able to supervise small children, or use the cooker because of the risk of seizures.

The many roles of a parent

Being a parent can be difficult because there are so many things that need to be done and there are lots of different roles that parents have to adopt. In the words of one parent:

“ When I look back at everything I used to do as a parent I find it quite amazing that I took it all for granted. Not only did I love and nurture my children, knowing when they were tired or needed a cuddle, but I also did so many practical things. I helped them to wash and dress, I cooked for them, took them to and from school, helped them with their homework, and – for the older children – acted as their personal taxi driver. I used to pride myself that they rarely saw me angry, I had a ready smile for everyone. Back then life seemed very busy, but full of happiness. Now I feel defeated by the smallest task. Just doing the washing or keeping the house tidy feels like too much for me. My patience is non-existent and I spend all my time shouting.”

(Sylvia, Tweedmouth)

Major problems reported by parents with brain injuries

Irritability and poor tolerance

Many brain injured parents complain that they do not have the patience they used to have. They find it difficult not to be irritated by small frustrations and their children in particular can be the source of feelings of irritation and annoyance. Small children can be very noisy, messy, and they rarely sit still! Many people say they are quicker to become angry after a brain injury and they find themselves shouting at their children more than they mean to.

Guilt

Sometimes parents say they feel guilty because they cannot do things for their children like they used to. They may feel bad because they have had a prolonged period of recovery time in hospital for rehabilitation. They may feel guilty because they do not take as much interest in the children as they used to. This is usually because of their own **emotional problems**, (e.g. **depression**), or because life is difficult to cope with because of **physical problems** and **fatigue**.

Case study: “I don’t know why, I just didn’t seem to feel the same way about the children as I used to. I think my motivation was badly affected; everything seemed like such an effort. I used to feel really guilty about it, as before my accident I was a real “hands-on” dad. It is a bit better now, since I have started to feel less depressed”.

(Jim, Seahouses)

Lack of confidence and self-esteem

Many parents find that, following a brain injury, they lose confidence in their abilities generally, and this, of course, affects their confidence in themselves as parents. They will sometimes leave decision making to the other parent, or try not to become involved in situations of conflict with their children. Brain-injured parents may sometimes feel they may have little or nothing to offer their children because of their disabilities.

Case study: “I realised that my confidence really took a knock after my injury. Because I was so worried about looking stupid in front of people when I forgot a word, I used to avoid going to shops. Now I prefer to let one of my daughters do all the talking when we are out, I find that I sort of hide behind them.” *(Laura, Alnwick)*

Multiple demands of parenting

Being a parent means having to carry out a lot of different kinds of tasks at any one time. After brain injury it can be difficult to ‘juggle’ all the different commitments. It can be particularly difficult if there is more than one child in a family, as children of different ages require different things from their parents. For example, a parent may cope well with older children who mostly speak up when they need something, but they may find it difficult with younger children who communicate their feelings using behaviour (e.g. clingy behaviour, temper tantrums, etc). Frequently, people say that after a brain injury it is difficult to do more than one thing at once, for example, help a child with homework while at the same time preparing a meal.

Practical problems

There are a wide range of practical difficulties encountered by parents with brain injury. These include not being able to drive, being unable to take part in family activities such as playing football, not being able to go on certain kinds of holiday, or play complicated board games, etc. For other parents [epilepsy](#) can pose problems, because of the risks involved if they have a seizure while caring for younger children.

Changes in physical appearance

Often after brain injury there are changes to physical appearance. In particular, parents report changes in facial appearance as being the most distressing. For example, there may be facial muscle weakness, visual problems, or skull defects. There may also be other changes in physical characteristics, such as changes in mobility and walking patterns. Usually children do adjust to changes in their parent's physical appearance, but there can be a period where children are afraid of the changes and they may react differently to the parent at first.

Most often, though, it is the parents themselves who feel different and this can impact on their self-confidence and self-esteem. Occasionally parents say that they feel that older adolescent children seem embarrassed about some of the physical changes.

Being focused on one's own recovery

Sometimes after a brain injury people become very focused on their own world and find it difficult to see things from other people's perspectives. In the early rehabilitation period, the person with the head injury is often very caught up with their own difficulties, trying to learn to speak, think, move, or remember as they used to. This can take a lot of energy and family time and sometimes children can suffer as a result. Older children in particular may be expected to cope with a reduction in time and attention from their parents, but they may find this just as difficult as younger children would.

Case study: "I never really realised just how much my daughter suffered while I was in hospital for all those months. I was just so caught up in my own worries and my own goals: all I could think about was learning to walk again. It took me a year of being at home before I realised just how much she had missed me and still needed me".

(John, Hexham)

Changes in children's behaviour

Many parents report that not only are they different after their head injury, but they find their children relate to them differently too. For example, if a child has been separated from a hospitalised parent for some months, they may find it difficult to readjust to the parent coming home. They may not be as affectionate as they used to be, maybe not wanting as many cuddles. Sometimes children seem not to respect the authority of their brain injured parent as much as they did previously and this can be very difficult for a

parent to deal with. Often a brain injured parent complains that they feel sidelined and that their child will only do as they are told for the other parent.

Feeling that children are ‘surpassing’ them

Occasionally parents with brain injuries say that they feel their children have overtaken them in their learning progress. For example, feeling that children’s homework is too difficult, or that children take advantage of their poor memory.

Changes in family roles

Often after a brain injury the whole family lifestyle and routine has to change. It may be that the parent with the brain injury can no longer work and becomes a full-time carer for the children. Or, it may be that the unaffected parent has to give up work to stay at home and look after the injured parent. Inevitably this changes the structure of the family and the routines. For example, some dads who have had a brain injury would much rather be working and find it difficult to be at home with the children all day.

Case study: “Everything changed after my brain injury. My wife had to give up work to look after me. I used to work away a lot and it was very stressful when all of us were together as a family all the time. We just weren’t used to it and all of us struggled with it at first. We had some terrible arguments.”

(Steve, Cramlington)

Changes in the spouse's behaviour

Occasionally, because the head injured parent requires help and support from their partner, they can feel a bit like one of the children themselves. Sometimes this is because the person needs to be reminded to do things, or because they need help with practical tasks such as dressing or washing. Similarly, it might be that after a brain injury a parent is poor at handling money, and relies on their partner to take control of financial matters. Because of these changes, parents report that their partner's attitude toward them has changed and that this affects their parenting role.

Case study: “Even my seven year old son started to notice that ‘daddy can’t remember things so mummy has to be in charge all the time’. That was because, in the early days after my injury, my wife always had to keep me right all the time, and she couldn’t trust me to remember anything. It made me feel like a kid myself.”

(Eric, Morpeth)

Emotional problems

Depression and anxiety are very frequent after brain injury. About 25 per cent to 50 per cent of people will experience **emotional problems** approximately one year after brain injury. If a parent feels depressed or anxious, inevitably it will affect the way in which they relate to their children. For example, parents who feel low may have problems with motivation, energy levels, and confidence. Parents who are anxious may find it hard to venture out and may prefer to always be near home.

Case study: “When I am having a bad day, I feel really nervous and it means I don’t want to go out anywhere. I worry about everything and I much prefer it when the children and all the family are safe at home.”

(Maria, Blyth)

Memory problems

Parents with brain injury report that having a poor memory can affect their relationship with their children. It may be that they find it difficult to remember what has happened a few days earlier and subsequently find it hard to share memories with the rest of the family. Other people find that their everyday memory problems mean it is difficult for them to take responsibility for their children.

Special issues

Step-parenting after traumatic brain injury

After a brain injury it can be hard to resume a role as a step-parent. For example, if the parent has difficulties remembering life before the brain injury, it might mean that they forget important details about their step-children or about events that have happened.

Sometimes, although a step-family may have worked well before the brain injury, there can be tensions after brain injury. An example would be a parent who has difficulties with irritability or temper control. Whereas they may have been able to “bite their tongue” beforehand and not say something they shouldn’t, it might now be much harder for them to do so.

Case study: “When I first got out of hospital I used to think that my stepson resented me because his mam used to have to spend so much time with me. Before my injury we used to play football together and we got on okay. I can’t do that now, and sometimes I think we have nothing in common anymore”.

(Neil, Gosforth)

Traumatised and injured families

On occasions, there may have been more than one family member involved in an accident which caused a brain injury. Sometimes children witness the trauma that caused the accident and they can develop emotional problems. Possibly a

child has had both parents involved in an accident and this may profoundly affect their sense of safety in the world.

Case study: “Our son was very clingy after our accident. He would only stay with one relative and he got very upset if my wife and I wanted to go out together for an evening. We realised that it was because he remembers the last time we went out in the car together, daddy did not come back for months.”

(Alan, Rothbury)

Case study: “My son was told that daddy was in a very bad car accident. A few weeks later the teacher showed my wife one of his drawings, it was a picture of me in a car that was on fire. It was very upsetting for us to see it and we realised just how traumatic it had been for him too. Our social worker suggested that we go to our GP and request some counselling for him.”

(Bill, Berwick)

Very severe traumatic brain injury

Where the person with the brain injury has been more severely injured, there may be very difficult issues to deal with. Usually it is the unaffected parent who has to cope with these issues, for example explaining to children what has happened and trying to find ways to help them understand the nature of any disabilities. Often there are legal issues that need to be dealt with too and this can be very stressful for the uninjured parent.

Case study: “My wife suffered a very severe stroke after a heart attack. She needs 24-hour care and she cannot do anything for herself. One of her rehabilitation goals at the moment is to help her be able to sit on the sofa at home. All the children are looking forward to the day when they can come and sit on her lap for a cuddle – they can’t do that while she is in her wheelchair. It has been very hard trying to explain to the children what has happened to their mum. The younger two especially don’t really know what it is all about. Our older two daughters understand and do their best to help out, but I worry that they take on too much responsibility for their age”.

(Peter, Tynedale)

Involvement of Social Services

Social Services become involved with families primarily to support them and offer advice if they are struggling with their new situation. Sometimes, if there are concerns about the welfare of children in a family, Social Services may need to help in other ways, for example organising extra practical help or social care before and after school. Very occasionally, where there are serious concerns, Social Services may need to intervene more formally and call a case conference or arrange assessments. An example might be when a brain injured parent has severe problems with anger control. In these circumstances the child will have their own social worker appointed to them, to speak up for them or act as an ‘advocate’. Case conferences give parents the chance to speak up about any concerns or difficulties they may be experiencing and which they want help with.

Advice and guidance



Overcoming irritability and poor tolerance

Take time out to calm down and walk away when necessary

Often the most effective way of dealing with irritability is to try and make sure you have the opportunity to calm down so that you avoid losing your temper.

For example

Situation: You are helping your child to tidy a bedroom and he/she wants to play with all the toys rather than tidy up. You feel yourself becoming irritated and think you are about to lose your temper.

Strategy: Leave the child to get on with tidying the room themselves, just for a few minutes, while you take the chance to cool down and collect your thoughts. When you feel calmer you can go back and take charge of the situation.

Some parents are concerned that if their child is being 'naughty' or demanding that it sends the wrong message to the child to leave the situation, i.e. If I leave the room when I am angry, my child will think *'if I go on long enough then dad/mum will get so annoyed they'll give up and leave the room'*. In these situations you might want to say something like, *"I can feel myself becoming irritable. I am going to leave you to think about your behaviour for a few minutes. Then I am going to come back and we can start again."*

Try to predict stressful situations and organise breaks for yourself

You may need to agree with your partner on times when you can have a break from the children. It is worth noting down times when you feel particularly irritated, to see if there are any patterns. For example, some parents find that the time when children first come in from school is very difficult. This is because children are often excited to be home and may make a lot of demands, such as wanting something to eat, wanting to go out, etc. If possible, you could negotiate for your partner or spouse to deal with the children at these times of the day, and in return take further duties later in the evening, e.g. at bath or bedtime. Or, it might be that the injured parent feels at their best in the mornings and would prefer to organise the morning routine.

Keep on top of mess and clutter

Some parents find they get very irritated by children's mess, for example, clothes or toys strewn around the house. If this is the case, it may help to ensure that children agree to keep specific areas of the house tidy so that you always have a quiet, tidy space to retreat to. Children, especially younger children, usually respond well to rules, so, for example, a new rule might be: *"You can play with your toys in your bedroom or the living room, but no toys are allowed in the kitchen."*

Avoid arguments and conflicts that go nowhere

With older children, the problem is often getting into lengthy and unproductive arguments. Teenagers in particular are very good at this and perhaps don't realise when their injured parent is becoming really annoyed until it is too late. At these times it is always best to walk away if you feel you are going to lose your temper. With teenagers it is usually best to be

honest about how you are feeling, so that they understand the impact of continuing an argument. For example, you may say, *“I am starting to get really annoyed now. I think we should leave this here and maybe talk about it later when we have both calmed down.”* To say this does not mean that you are backing down in an argument, merely that you are postponing the discussion to a time when you are both calmer.

‘Buy time’ for yourself so you can think about how to discipline a child

It is important to notice signs of rising anger before the situation gets out of hand. If you become agitated and annoyed with a child, and you don’t know the best way of handling the situation, but do not want to lose your temper, it is a useful strategy to ‘buy some time’.

For example

Situation: Your child deliberately throws his food while at the table, after you have already asked him not to.

Strategy: Say, *“I am very cross that you threw your food. I will have to think about how I am going to deal with you, so you learn to do as you are told and not throw food.”*

Then consult with your partner/spouse about a suitable way to deal with the behaviour. However, with younger children, it is best to do this as soon as you can, e.g. within half an hour. At the time that you implement the sanction/punishment you will need to remind your child why it is happening, e.g. *“You won’t be allowed any sweets this evening because you threw your food at tea time. I hope this will help you to learn not to throw your food.”*

Build a positive relationship with your child

It is also important to be able to generally feel positive about your child and your relationship. This makes it easier to cope with the everyday irritation that you may feel. It is also easier to discipline a child within the context of a strong positive relationship with them. See the section on '[Dealing with changes in children's behaviour](#)' for tips on building a positive relationship.

Key point

It is important to remember that all parents get irritated with their children on a daily basis! The key is to handle your irritation well, without letting the situation escalate unnecessarily, and taking steps to avoid things getting out of hand.

Overcoming emotional difficulties

People with brain injuries very commonly experience **emotional problems** following their injury. Usually these difficulties will improve as they adjust to the consequences of the brain injury. However, this may be a long, slow process. The following are some tips which may prove helpful:

Accentuate the positive and eliminate the negative!

Sometimes when people become depressed their thinking becomes very negative and 'black and white'. For example, you may pick up on all the negative aspects of the relationship with your child, but fail to acknowledge all the positive aspects. It is important then to recognise your strengths as a parent instead of dwelling on the negative.

Situation: You find yourself thinking, *'I am no good as a parent because I can no longer drive.'*

Strategy: Try to challenge your thinking. Sometimes this is easier if you put yourself in someone else's position. For example, you might say to yourself, *'Well, if my wife/husband said this, what would I say to them?... I would say, 'Yes it is true that you can't drive now, but think about all the things that make you a good parent. What are the things that you can still do that are just as important as driving?'*

Tackle avoidance head-on

Many people, if they are feeling anxious or depressed, find that they start to avoid things that they find difficult. This may seem like a good strategy, but unfortunately it only serves to make the thing you are avoiding more difficult to face.

Situation: You avoid going to the school playground to collect the children because of worries about not being able to think of anything to say to other parents in the schoolyard. If you avoid this for a while, before long it seems a very difficult thing to stand and wait in the playground and it may actually mean that people are more likely to come up and talk to you – something that you find difficult – because they haven't seen you for a while.

Strategy: Instead of avoiding the situation, mentally prepare for what you might say if somebody talks to you. For example, think of a few stock phrases or answers to say if somebody asks how you are, and wherever possible try to turn the conversation round so that you are asking about them instead of feeling you have to explain yourself. If that seems like too big a step, then perhaps at first take a relative or friend with you.

Talk over your concerns with your partner or spouse. Often they will be the best person to provide contradictory evidence to disconfirm your negative beliefs. For example, in the words of one parent, Jonathan: *“When I first had my accident, I used to think that I was a rubbish parent. I thought that my daughter felt she could not rely on me because there were so many things I could not do for her anymore, and I had abandoned her whilst in hospital for such a long time. However, my wife told me that while I was in hospital our daughter used to pray that I would get better every night. I realised then just how much she needed me. When my wife told me that, I realised that no matter what problems I had I would always be her dad.”*

Get professional help when it is needed

If you find that depression or anxiety has become a big problem, it may be beneficial to ask your GP for some professional help.

Usually a combination of medication and ‘talking therapies’ can make a big difference in helping people with emotional difficulties after a brain injury. Where there are real concerns about somebody’s emotional state, for example if they talk about suicide or wanting to ‘end it all’, it is usually the best strategy to seek professional help.

Dealing with changes in children’s behaviour

Most children will adjust to the changes in their brain-injured parent eventually. However, there may be some time during which your child does seem to react differently to you. It is important to recognise that this is a normal process.

Children will have had to cope while their injured parent was in hospital and it can be difficult for them to readjust to the new life once their parent comes home.

Gain a better understanding of your child's behaviour

All children are different and may react in different ways to the new situation. Some children may become more anxious and clingy; others may seem not to respect authority as much; others may seem cool or indifferent to the injured parent. It is worth remembering that the child is doing their best to work out what the new scenario is and how they can deal with this. Some of their behaviours may reflect this internal struggle that they are having.

After understanding comes patience...

Try to be as patient as possible with the children. Remember that they have as much emotional adjustment to make as the parent. It will be important to talk to them about how they feel about the changes that have occurred within the family. Possibly in the first instance you may decide that the uninjured parent may be the best person to do this, or both parents might want to do it together.

Re-establish the authority of the injured parent

For children who no longer seem to recognise the authority of the injured parent, it is sometimes useful for the other parent to defer decisions to the brain-injured parent.

Situation: A child always goes to mum to ask, "*Can my friend stay for a sleepover*". He never goes to ask dad (who has a brain injury) any more.

Strategy: Mum deliberately says, *“I am not going to say yes until I have asked dad what he thinks. He will have the final decision about this.”* In this way the unaffected parent supports the brain-injured parent in re-establishing their authority.

Build a new relationship

For parents who feel that they no longer know their children, or who feel negative about their relationship, it is important to build up a positive relationship again. The best way to get to know a child better and re-build a relationship is to spend time with them doing activities that they enjoy. This doesn't mean you have to take them to an expensive theme park. You can spend time just being with the children at home. Even watching children while they play and chatting to them is a good way to start.

The key is to show interest in them and their world. Get to know their likes and dislikes, and their ways of being and coping: What is guaranteed to delight them or excite them? How do they communicate or behave when they are angry, frightened or anxious? How do they cope if they find something hard? Do they respond well to praise? Are they competitive and do they like a challenge?

Seek professional help when it is required

In some instances, if a child is clearly distressed or their behaviour becomes difficult to manage, it may be sensible to seek professional advice and guidance from child services. Again, your GP should be the first port of call.

Dealing with memory problems

It is difficult for injured parents who have forgotten the birth or the early years of their children. Unfortunately, in many cases, these memories will never be recovered and both parents and children will have to find ways to deal with this loss. However, it is useful for the whole family to get together and look through photograph albums, and ask the unaffected parent to reminisce and tell anecdotes about the stories behind the pictures. The important thing here is that the injured person is still sharing in the memories, even if they cannot recall these memories firsthand themselves.

For parents with everyday memory problems that cause difficulties in helping their children remember a daily routine, it is important to keep the household as organised as possible and running smoothly. This helps the brain-injured parent to compensate for their memory problems. For example, you might use a notice board, calendar or whiteboard in the kitchen which indicates all the children's weekly routine, (e.g. which equipment they need to take to school on what day, and what after-school activities they may have). 'To-do' lists, notes and electronic reminder systems may also be invaluable in remembering to carry out child care related activities. (see '[Further reading](#)' for more sources of information on memory problems).

Key point

Remember: Being a parent is about being a parent in the here-and-now, and in the future, not just in the past. You may not be able to change the past, or remember the past, but the future is still in your hands. Children need parents for the rest of their lives, not just as children.

Overcoming cognitive and practical problems

Start off small and work your way up

It is important to remember that while you may not be able to cope with complex tasks or situations now, this may not always be the case in the future. Most people with brain injuries will learn to adapt and become better at dealing with difficult situations. It can help to try simplify things and start with small goals.

Situation: A family has two boys who are very boisterous. In the past, both children would often bring two or three friends home to play after school. Mum, who has had a brain injury, has attentional problems and feels she cannot cope with all the noise and chaos.

Strategy: Instigate a new rule: Each child can bring one friend home from school once a week. On those days dad arranges to come home early from work to help cook the evening meal. When mum feels more confident with this arrangement, she plans to prepare a meal the night before so that it can be heated in the microwave and her husband can stay longer at work. At some point in the future she hopes that she will be able to let the children have more than one friend at home at a time.

Key point

Generally it is best to start off with small goals and then expand from here as you become more confident and proficient.

Adaptation - try to find ways round the problem

Situation: Following her head injury, Susan finds that she is often tired, but does not sleep well at nights. She finds that in the afternoons, or when she feels very fatigued, she becomes much more irritable. She takes her 3-year-old son Ben to playgroup three mornings a week and copes well at the time, but by the afternoon she is exhausted and frequently loses her temper, which makes her feel very guilty and inadequate.

Strategy: On the three mornings that Ben goes to playgroup, Susan's mother comes to make his lunch. She only stays for an hour and a half, but it is long enough for Susan to go upstairs and lie on the bed for a while. Susan finds that, although she doesn't always sleep during this time, the rest helps her to 're-charge her batteries' for the rest of the afternoon.

Dealing with major role changes in the family

Help the injured parent to retain their parenting roles

Major role changes in the family can take some getting used to. Where there may have been major role changes, it is always important to recognise that the injured parent retains their role as mum or dad first and foremost. It is important that family carers and paid carers try to facilitate the injured parent doing the things they always used to do for his children, rather than doing the tasks for him.

Situation: A father gets confused about what time he should give his two small children juice or a snack. Sometimes he gives them their snack many times in a day, whenever they ask. Mum is worried that he is giving the children too many

biscuits and that then they don't eat their meals, so they have decided that only she, and not dad, will be in charge of giving the children snacks.

Strategy: The Occupational Therapist involved with the family can help to programme reminders into an electronic organiser for the father, so that he is prompted to give the children a snack only once in the morning and once in the afternoon. Now both parents are happy that dad can give the children snacks as well as mum.

Situation: A mum who has had a brain injury has a very poor memory and is unable to cope with handling money. She used to do all the family grocery shopping, but now she tries to avoid this because she becomes very anxious about 'looking stupid' at the checkout. When she does go shopping she frequently forgets to make sure that there are enough supplies to make up the packed lunches for her husband and the children. This problem is causing frequent arguments, which increases the tension in the house.

Strategy: Dad starts a new checklist system, so that every Saturday morning mum checks the supplies needed for packed lunches for the following week. The family's social worker organises two hours a week of home care for someone to help mum with the grocery shopping. Mum changes her old routine, so that now at 9pm every evening she makes all the lunches ready for the next day. This helps to reduce the chaos and confusion of the morning routine.

Learn to be flexible and try to accept inevitable changes

As marital partners and parents, we often get settled into fixed and comfortable routines. These are usually determined by our skills, interests and our personalities. For example, in one

family, it is dad's job to go to work and support the family, sort out the garden and do the DIY. He also fixes broken toys, maintains all the family's bikes, carves the Sunday roast, tells bad jokes, plays darts on a Friday night at the pub with his friends, puts up the Christmas decorations and dresses up as Santa every year. After his brain injury, he may not be able to work and he may have to learn to do housework and cooking while his wife goes back to work. Although this might be difficult for all the family to accept at first, often it is something which everyone has to come to terms with because there seems to be little other choice. A family that can accept this and be flexible about changing roles will cope and adjust well to their new situation. Dad may not be able to do all the other things that he used to do, but even if he can't manage some of the things, there will always be the chance for new family routines and traditions to develop. For example, dad may not manage to mend broken toys and bikes any more, but you will still find him every Christmas carving the turkey and telling bad jokes.

Work together as a couple and maintain a united front

When there are major role changes in the family, it is important for both parents to work on retaining a strong bond as a couple. This is crucial if the marriage or partnership is going to survive what is a very stressful time of readjustment. Both partners will need to value each other's (and their own) contributions to family life. Both parties can help by showing appreciation for what life must be like for the other now that it is so different. For example, a husband can show appreciation of the frustration that his wife must feel now that she can no longer provide physical assistance to their young child because of her hemiparesis (one-sided weakness). For her

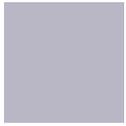
part, she can show her husband that she understands how under pressure he feels because he is working and having to get up for their daughter during the night. They can *work together* on finding ways round the difficulties of getting her settled into a new night-time routine.

Maintaining a 'united front' is also crucial when dealing with issues of disciplining children. Where there have been major changes in parenting roles, differences in parenting style often emerge. Sometimes these differences can be exploited by children!

Situation: After his brain injury, Michael took on the role of 'house husband' as he could not return to work. His parenting style was to be very relaxed with the children, giving them a lot of freedom to play out whenever they wanted to. His wife Diana, however, always preferred to supervise the children closely and liked to know exactly where they were playing and with whom. At weekends, Diana and Michael would get drawn into bitter arguments about what the children should be allowed to do. Diana was becoming very annoyed that the children would always say, "But dad lets us do that when you are not here"!

Strategy: Michael and Diana decided to have a regular discussion about how they were handling the children. Now, every fortnight, they get a babysitter and go out for a meal. They spend the first hour talking about the last two weeks and how the children have been. Then they try to agree on how to manage any discipline issues that have arisen. For the rest of the evening they relax and enjoy some time together without the children.

Further reading



The following books are available from Headway and provide a good introduction to brain injury and its effects:

- Clare, L. & Wilson, B.A (1997) *Coping with Memory Problems: A practical guide for people with memory impairments, their relatives, friends and carers*. Pearson Assessment: London.
- Daisley, A., Tams, R. and Kischka, U. (2008) *Head Injury: The Facts*. Oxford University Press: Oxford.
- Johnson, Jo. (2011). *My Parent Has a Brain Injury*. RWP Group: Littlehampton
- Powell, T. (2004) *Head Injury: A Practical Guide*. Speechmark Publishing Ltd: Bicester.
- Powell, T & Malia. K. (2003) *The Brain Injury Workbook*. Speechmark Publishing Ltd: Bicester.
- Wertheimer, A. (2008) *A Dented Image: Journeys of Recovery from Subarachnoid Haemorrhage*. Routledge: East Sussex.

Headway also produces an extensive range of freely downloadable **booklets and factsheets** covering the problems that brain injury can cause. Titles of particular relevance to the information in this booklet are:

- *Caring for someone with a brain injury*
- *Coping with memory problems – practical strategies*
- *The effects of brain injury and how to help*
- *Managing anger after brain injury*
- *Managing fatigue after brain injury*
- *Memory problems after brain injury*
- *Psychological effects of brain injury*
- *Redeveloping skills after brain injury*
- *Returning to work and education after brain injury (factsheet pack)*
- *Supporting children when a parent has had a brain injury*

For further information visit www.headway.org.uk , or contact the helpline on **0808 800 2244**; email: helpline@headway.org.uk

Useful organisations



Assist Trauma Care

11 Albert Street

Rugby CV21 2RX

Helpline: 01788 560 800

Web: www.assisttraumacare.org.uk

ChildLine

NSPCC Weston House 42 Curtain Road

London EC2A 3NH

Helpline: 0800 1111

Web: www.childline.org.uk

Disabled Parents Network

Web:

www.disabledparentsnetwork.org.uk

Family Lives

15-17 The Broadway, Hatfield,

Hertfordshire AL9 5HZ

Helpline: 0808 800 2222

Web: www.familylives.org.uk

Families need Fathers

134-136 Curtain Road

London EC2A 3AR

Helpline: 0300 0300 363

(9am-10pm weekdays

10am-3pm weekends)

Web: www.fnf.org.uk

Gingerbread

520 Highgate Studios

53-79 Highgate Road

London NW5 1TL

Helpline: 0808 802 0925

Web: www.gingerbread.org.uk

Home-Start UK

The Home-Start Centre

8-10 West Walk

Leicester LE1 7NA

Helpline: 0116 258 7900

Web: www.home-start.org.uk

Relate

Premier House

Carolina Court

Lakeside

Doncaster DN4 5RA

Tel: 0300 100 1234

Web: www.relate.org.uk

About Headway

Headway – the brain injury association is a charity set up to give help and support to people affected by brain injury.

A network of local Headway groups and branches throughout the UK offers a wide range of services including rehabilitation programmes, carer support, social re-integration, community outreach and respite care. The Headway helpline provides information, signposts to sources of support and rehabilitation services, and offers a listening ear to those experiencing problems. Other services provided by Headway include:

- Supporting and developing local groups and branches
 - Promoting understanding of brain injury and its effects
 - An award-winning range of publications on aspects of brain injury
 - Accreditation of UK care providers through the Approved Provider scheme
 - A comprehensive, award-winning website
 - Campaigning for measures that will reduce the incidence of brain injury
 - Providing grants from our Emergency Fund for families coping with financial difficulties
 - Headway Acute Trauma Support (HATS) nurses to support families with loved ones in hospital
- Freephone helpline: 0808 800 2244
(Monday–Friday, 9am–5pm)
 - Telephone: 0115 924 0800
 - Website: www.headway.org.uk
 - Fax: 0115 958 4446
 - Email: helpline@headway.org.uk

Parenting after brain injury

by Dr Alex Goody

This booklet has been written to help those parents who have had a brain injury understand how their injury has affected them in their role as a parent.

