

Having a brother or sister with an ABI

The Child Brain Injury Trust is a national charity supporting anyone affected by childhood acquired brain injury. The following information has been developed to help the reader understand more about brain injury and some of the associated issues. Every effort has been taken to ensure the information is accurate and up to date.

You may want to ask your parents to watch one of our e-Learning sessions all about how brain injury can affect everyone in the family. They can choose from any of the sessions by visiting <https://childbraininjurytrust.org.uk/how-we-help/e-learning-library/> or clicking on the links below if you are reading this online:

- **Impact on Younger Siblings - Support Strategies**
- **The Impact of ABI on Siblings**

If some of the words in this Factsheet are too difficult for you, ask a friend or a grown up to read them through with you.

It can be really tough when your brother or sister gets a brain injury. You might be feeling....



It might be hard to know what to feel and whether it is even right to feel anything at all because this did not happen to you. It is important to remember a brain injury does not only affect the person who got hurt/who is unwell; it affects the whole family so it is understandable and normal for you to have these feelings and emotions about what has happened.

Brothers and sisters like you often feel forgotten when a brain injury occurs because your parents will naturally focus on your brother or sister who has been hurt and spend most, if not all, of their time to make things better for him or her, with lots of time spent at the hospital, or more time than before helping them do things they can no longer do.



Below is an account from a sibling in this situation:

“Mum went into practical mode and was constantly at the hospital. She told me I should stay at home and they would find someone to be with me. Fobbed off, that’s what I think now. I was shoved to one side so I she didn’t have to worry about me. I realise now that Mum and Dad did not mean to make me feel

left out, it was just that my brother’s injury had to take priority; but no one explained that to me, so I felt very left out”

Thoughts and feelings

It is OK to not be OK about all of this; many other brothers and sisters also feel:

- Mum and Dad have forgotten about me
- Everything has changed, and not in a good way
- People are not explaining things, so I do not understand what is happening
- I feel really guilty that I was not there on that day, or for thinking about myself and how left out I feel at such an awful time. I also feel guilty that I want my brother/sister to be how they were before.
- I’m worried about my future, my brother/sister and/or our family as a whole
- Frightened that the same thing may happen to you, if your sibling’s injury was caused by an illness of some kind; or thinking that you too could have the same accident.
- It’s not fair, I have to do more jobs around the house now because my mum doesn’t have time to look after my brother/sister and do these things.....and then I feel guilty for being cross about this
- I’m not special enough and not loved as much anymore because mum and dad spend all their time doing things with or for my brother/sister

All of these feelings are normal thoughts for someone who is going through the difficulties you are, after your brother or sisters brain injury – don’t feel it is wrong to have these feelings.

When your sibling with a brain injury returns home from hospital it can be difficult for you to make sense of why your brother or sister is getting more attention or is acting differently, particularly if they look much the same as they did before. It does not help that we all tend to think that leaving hospital means that the person is better when in fact leaving hospital can be the starting point for a whole host of new concerns and problems for your sibling and the family as a whole.

- **“It’s hard to concentrate; I worry about what’s happening at home.”** Try not to worry and spend some time with friends just having fun.
- **“People seem to think that everything is fine at home now because more than a year has passed, but things are getting worse, not better”.** Sometimes it can take a long time for your family to adjust to what has happened, and your friends may have forgotten about what your home life is like – even a long time after your brother or sister got their brain injury. Just remember you are not the only one who is having these feelings, things will get better.

How things may have changed

Other siblings in these situations talk about the following areas when talking about how life has changed since their brother or sisters brain injury:

- Schoolwork – not having the help you need to do homework
- Friendships – not wanting to have friends round or have sleepovers, because you don’t want them to see what your brother or sister is like since their injury
- Missed experiences – not being able to have the sort of holidays you used to have; no longer being able to go out for the day; not having the money to pay for school trips that your friends are going on.
- New rules – having to have new family rules to suit the new way that your family now does things



Asking for help and telling grownups how you feel

It can sometimes be much harder for you to express how you feel, all those emotions of anger, loneliness, feeling left out and unloved. Try and talk to your parents, relatives, family friends or another person that you feel comfortable to talk to, this can make a big difference to how you feel and may help to get worries or concerns off your mind.

Everyone deals with things in different ways, and it is normal to have mixed feelings. There are lots of brothers and sisters who have been through similar situations as you. Here are some useful tips they have used:

- If you want to know more about what is happening, ask.

- Try talking to Mum and Dad and explaining how you feel; yes they are coping with a lot too, but it is important that they understand about how you feel to.
- If this is too difficult, think of someone else that you get on well with and try talking to them about how you are feeling. You could ask an older brother or sister, or an aunt or uncle, or grandparents, even your teacher at school; it might be a friend, or even a neighbour.



•If you cannot work out exactly what you want to say, try writing it down. It might be a letter, poem, song or a diary. Or you could draw a picture to show how everyone how you feel. You don't even have to show anyone what you have written or drawn, but it might help you to figure out how you are feeling.

You might find you sometimes need somewhere to escape to, away from the noise and noise of your daily family life. Ask your parents if you can have:

- A room to escape to – it could be your bedroom with all the things you need to help you feel better, like TV, games, listening to music.
- Advice on what to do if your brother or sister is having a session of bad behavior; it could be that you just walk away to your room.
- Permission to tell them if your brother or sister gets angry and hits or hurts you; let them know what was happening at the time.
- Some special time at least once a week where it is just them and you; this could be a shopping trip with mum, or a visit to a local wildlife park, or even just sitting together without your brother or sister to watch a film and have a cuddle.
- Lots of reminders on calendars to make sure they never forget to come to your school concerts and plays.
- Time to play with your brother or sister to try and build your friendship back to how it used to be, you could watch a film together or play a game.
- Family time where you all spend time together having fun.

It'll be alright in the end – rearrange how you think



There are some good things that often come out of these type of difficult situations; having a brother or sister with an ABI often makes their siblings much stronger and more capable people because you have to learn to grow and mature much sooner than most of your friends. This also means that you are potentially going to be more capable in life and be independent sooner than your friends. Which is something that not everyone can do.

In your pack you have some booklets and stories which we hope will help you to understand that you are not on your own, and that if we try to rearrange how we view the situation, how we feel about what has happened is really just in our heads, and with help we can overcome the hard times.

We also hope you find the Shapeshifter book amusing too – does it remind you of your brother or sister?

We support many children who have a brother or sister that have an ABI and here are just some of the things that they have told us:

Lucy B



“My name is Lucy and I am 12 years old. When I was 10 my 14 year old sister was diagnosed with a brain tumour. She was ill for a year and took up a lot of my mum's time, so I was often left out as she needed my mum more than I did. We were told about her brain tumour the night before my other sister's birthday, she was 17. My little brother was 3, he is deaf and a handful as he has ASD, so my mum was kind of busy. My dad doesn't live with us and he didn't know how to support us all so I felt lost. I was often lonely, left out, jealous of all the time and attention my sister got, even though I knew it wasn't her fault I felt forgotten. After her tumour was removed Ellie was in hospital for 3 weeks, she had a stroke and couldn't walk or talk. She was angry a lot of the time and I didn't know how to deal with that as we had always been so close. I missed my mum and my sister and knew I had to behave but I still struggled and needed an early help worker at school to help me manage my emotions.

I attend the same secondary school as my sister and I'm known as Ellie's little sister which is great, as even though she has had nearly 2 years off of school she can walk, talk, and is taking her GCSE's she is my annoying role model! I still struggle with how much time she has with my mum that I don't get even though me and mum have date nights and I still often get forgotten about which makes me angry and sad, but mum tries her best even though she works and is a student nurse. I am so lucky my sister is still here but because of her ABI her personality changes at the click of fingers, she says things she doesn't remember and they can be hurtful. I'm still trying my

best to be good, but sometimes I want to shout what about me. I wish I had someone to talk to sometimes, and there have been times I wish it was me who had been poorly then I think how selfish I'm being and my mum tells me how proud she is of me and I smile. Living with a sibling who has a brain injury is hard, being teenage girls who share a room adds pressure to that but I know it isn't my sisters fault and I try to make allowances for that, but sometimes I wish her brain tumour had happened to someone else. I love my sister, but she can be really difficult to live with."



Ellis Anderson

"Having a sister with a brain injury can be challenging sometimes, because everything has to go at a slower pace, so she doesn't get tired easily."

Jessica Hunt

I feel sad because everybody asks about Aiden because he had a brain tumour and they don't ask about me. Sometimes I feel jealous because Aiden gets more attention than me. When Aiden was in hospital, I felt sad because I couldn't see mummy, daddy or Aiden!



Oliver Hedges

My name is Oliver and I am aged 10. It feels a little bit depressing because sometimes I say something and my sister will say the opposite, even if I explain to her why I said it.

My sister can also be argumentative about nothing. For example – if I am putting on something on the TV that she likes, my sister will tell me that I am naughty. I say to her "well you love watching this don't you" and then my sister would normally shout at me and scream at me which can sometimes actually get quite annoying!

It can also be joyful because sometimes my sister will say something or do something that is HILARIOUSLY funny!