

A Teen's Guide to Brain Injury



HEADWAY
Brain Injury Services & Support

This book is an attempt to try and break the silence, to clarify some questions, fears and concerns that young people may have about brain injury and the effect that it may have on their loved ones.

In making this book we drew from the experiences and wisdom of young people who have already been through this, who have lived alongside brain injury for many years. We thank them for their insight and openness.

We would also like to thank the Dormant Accounts Fund, the ISPCC and Headway, whose expertise and support made this book possible.

The Editorial Team.



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Tá faomhadh an Rialtais i gcomhair maoiniú as Ciste na gCuntas Díomhaoin ag an Tionscadal seo.



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www.carf.org
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Your brain is the command centre of your body. It controls everything you do: how you think, how you feel, how you move, even what you like to eat. Your brain is also very complicated. It's made up of loads of different parts, each one with its own job to do.

If you are unlucky, your brain could get hurt and injured. You might fall off a wall, get a bad hit or kick to the head, or be in a car crash. Sometimes being sick can cause a brain injury; strokes, aneurysms, meningitis, tumours and hydrocephalus can all do damage to the brain.



Brain injury can make you feel and act like a different person. It can be hard to understand why this happens - you can't see your brain, so you can't see the injury, it doesn't always make sense.

If you break a leg that makes sense, you know you can't walk because your leg is healing but you can watch it mending, feel it getting stronger. Your leg may be badly hurt, leaving you with scars, or a limp. This can happen to the brain too. We can't see it, but the scars of the injury are there.

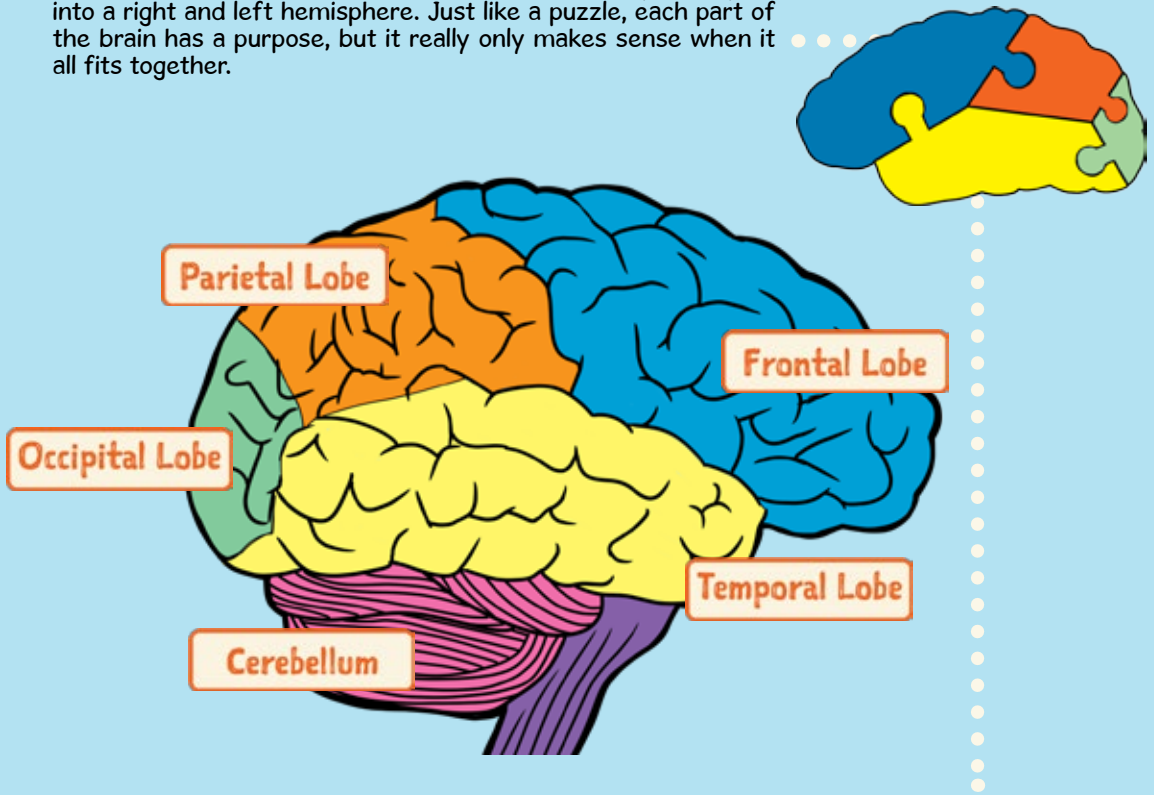
Perhaps you know someone with a brain injury. Perhaps this person seems different. Perhaps they feel like somebody new. This book is going to take you through how the brain works and help you to understand why.

The inside of the brain is sometimes described as being like a complicated network of roads running through a city. In the city, the roads are for carrying people in cars from place to place on their journey. The roads intersect and have junctions, winding and criss-crossing so that cars can drive wherever they need to go. If the roads were straight and never joined up, people would never be able to reach more than one destination.



Inside the brain, information is carried in much the same way. Instead of roads there are synapses and instead of cars carrying people there are neurons carrying information. There are billions of neurons and synapses twisting and turning all over your brain, working hard to make sure the information you need gets to the right place at the right time.

When we talk about the structure of the brain it can seem a bit like one of those 3D puzzles you have to slot together. The cerebrum fits on top of the limbic system and cerebellum, which slides on to the brainstem, and all this can be pulled apart into a right and left hemisphere. Just like a puzzle, each part of the brain has a purpose, but it really only makes sense when it all fits together.

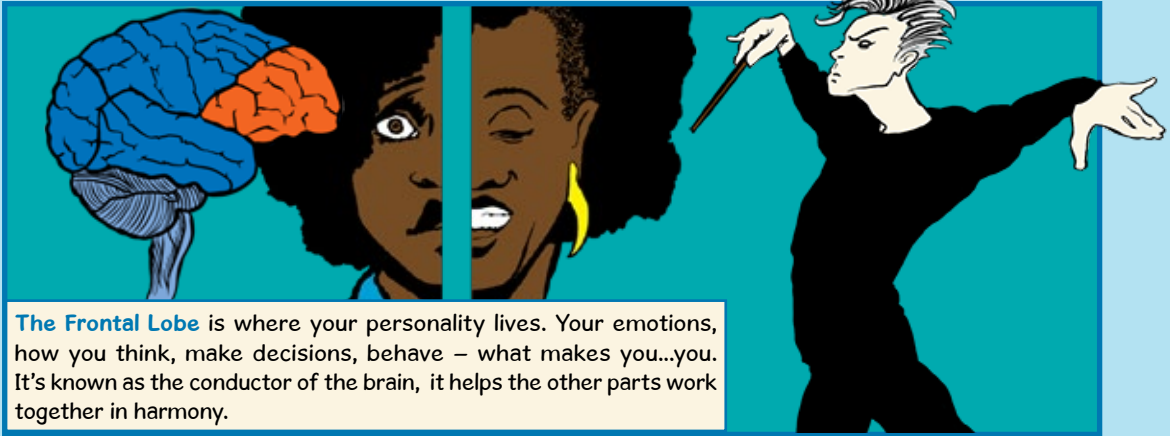


The cerebrum is the largest part of the brain, the top bit that looks like two halves of a walnut. It's made up of four lobes (frontal, parietal, temporal, occipital), the sensory cortex, motor cortex and visual cortex. Underneath the cerebrum is the limbic system. This is the oldest part of the brain, meaning it was the first part to evolve back before we were cave people.

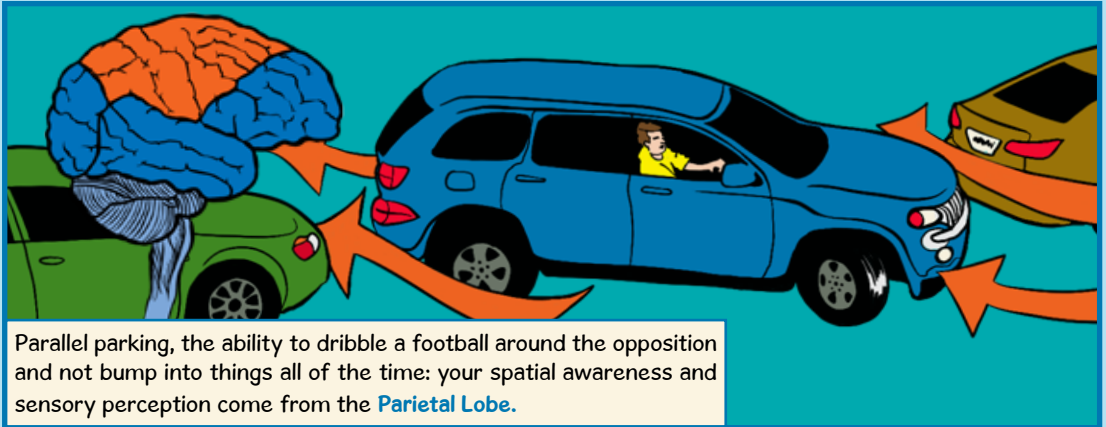
The limbic system controls our fight or flight response, it lets us know when danger is coming. It's also important for the ability to feel empathy, making new memories, and automatic functions like body temperature and breathing. Sitting behind the limbic system is the cerebellum, a small wrinkly ball that helps with regulating balance.

The whole brain can be split into two distinct halves called hemispheres. You might have heard that we are divided as a species into right-brained and left-brained people. The lefties are logical and really good at maths, while the righties are creative arty types. This isn't quite the case - we all use and need both sides of our brain to work at full capacity to get us through life. We don't shut one side off in favour of the other, It's just that in some people one hemisphere may be shouting a little louder.

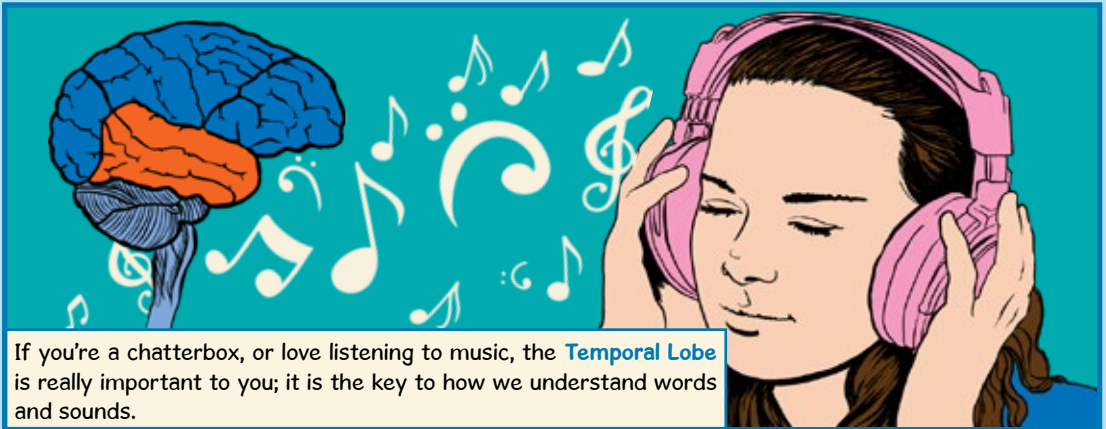




The **Frontal Lobe** is where your personality lives. Your emotions, how you think, make decisions, behave – what makes you...you. It's known as the conductor of the brain, it helps the other parts work together in harmony.



Parallel parking, the ability to dribble a football around the opposition and not bump into things all of the time: your spatial awareness and sensory perception come from the **Parietal Lobe**.



If you're a chatterbox, or love listening to music, the **Temporal Lobe** is really important to you; it is the key to how we understand words and sounds.



The **Occipital Lobe** is where we take the images captured by our eyes and make sense of what we are seeing – a bit like developing the film from a camera. It's how we know we are looking at things and people rather than a blur of colour.



For most of us, we will go through life with our brains working at full throttle. We will hold on to our memories and make new ones. We will keep talking and listening and chatting, and maybe even learn to do that in different languages. We will run and jump and play sports and dance. We will laugh and cry, and shout and scream, knowing when that is appropriate and learning to work with it. We will love, and lose love, and win it again. We will dream and hope to make those dreams a reality. We need our brains to work with and for us to make all this happen. We need for them to be healthy and free from injury.



After a brain injury, we can stop working at full throttle. Just like any injury to any other part of our body, what happens after depends on how badly we hurt ourselves. Some brain injuries are like cuts and bruises - sore for a while, but they'll heal in time. Some are more like a badly broken leg - it takes much longer to heal and might not be the same as before, maybe you'll limp and walk more slowly now. Some brain injuries are like losing a leg. The leg will never grow back, but you can learn to adapt, use your other limbs and work with the big change to your body.



Some people will be unlucky. They will get sick, or they will have an accident that leaves them with a brain injury.

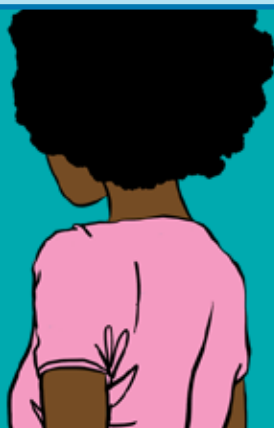


The next few pages will take a look at what can happen after a brain injury, and how it can be very different for each person, depending on what part of the brain they hurt and how badly.



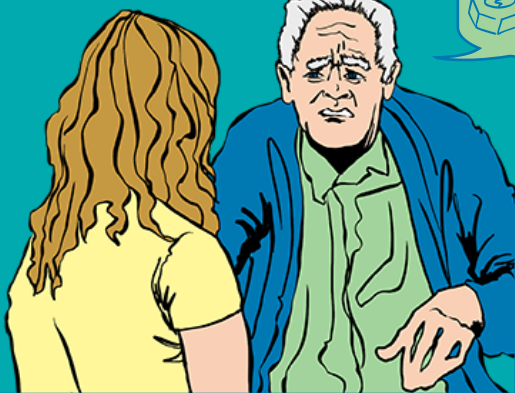
...um...

Frontal Lobe damage is most common after falls, car crashes and assaults. Injury can mean the orchestra of the brain is without its conductor. It can be hard to make decisions and think straight. Emotions can be overwhelming and hard to control. Your personality can change completely.



OUCH!!

The Parietal Lobe helps us to place ourselves physically in the world and make sense of what is around us. Damage here can lead to walking into things and disorientation. Recognition of numbers and the ability to spell may also be affected.



Perhaps the most commonly damaged part of the brain following a stroke is the **Temporal Lobe**. This is simply because of where it is located and how clots form and enter the brain. Our language centre is based in this lobe, so words and communication can be badly affected.



The Occipital Lobe right at the back is again most commonly damaged following assaults, falls and crashes. Damage to the interpretation of images received through our eyes can result in double vision or colour-blindness.





Sight, smell, hearing, taste, touch; our primary senses are the tools with which we make sense of and understand the physical world around us.



With every passing millisecond our brain takes in more information through our senses than we could possibly imagine. Some of this information is processed and stored but some the brain lets go of, otherwise we would feel overwhelmed all of the time.



To do this we have a sort of sensory filter system in our brain, like a sieve that lets the water out but catches the pasta. This filter helps to catch all of the sounds, smells and images that we need, letting go of whatever we don't have to pay attention to in that moment.



Brain injury can break this filter leading to sensory overload. Something as small as you having a conversation in the same room as someone with a brain injury who is trying to watch tv or read a book, can be too much for some people.



Their over-sensitive senses could hear that conversation as if through a megaphone.



If the filter gets broken, all of the information could come flooding loudly and brightly into their brain at once. This can be so difficult for some people to bear that it can feel almost physically painful.



They may shout at you to be quiet or stop, for it all to stop. They may need to just leave. They may need to be alone, to be quiet, to lie down. And they may not be able to explain to you why.



Emotions help us to experience the world and to interact with other people. A shared emotion creates understanding and intimacy. Being able to show joy, anger, sadness, fear, disgust and surprise helps to us express ourselves fully and freely.



As we get older we learn that we can feel emotions at different levels. It's a bit like the volume control on a TV, our emotions can go from silent to moderate to really, really loud.



Growing up, emotions become more complex and we develop a greater awareness of them. We learn the ability to control these different levels - we take charge of the remote. We start to know which emotions are appropriate for which situation.



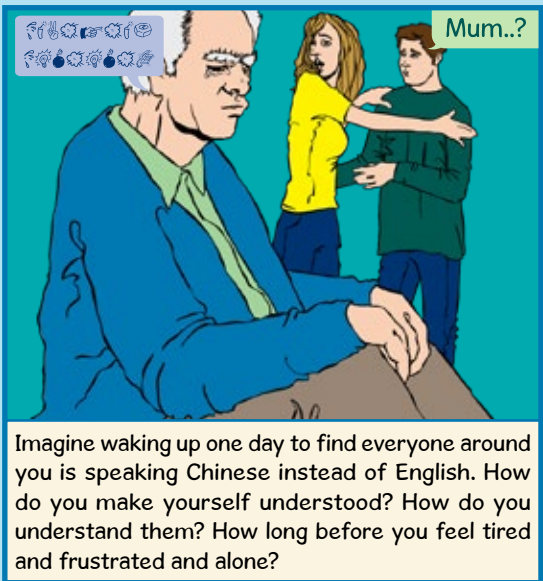
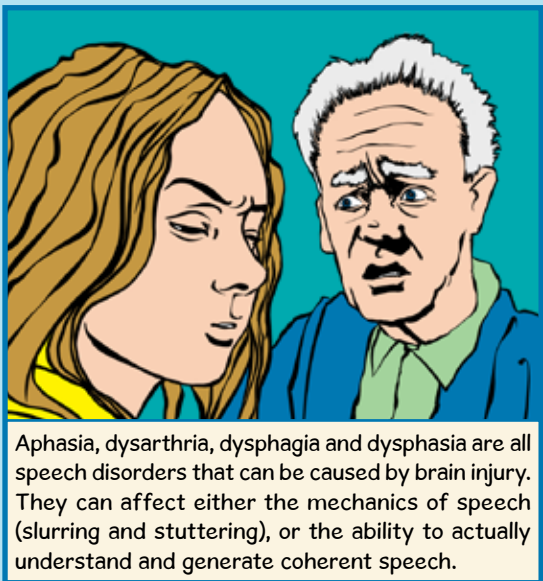
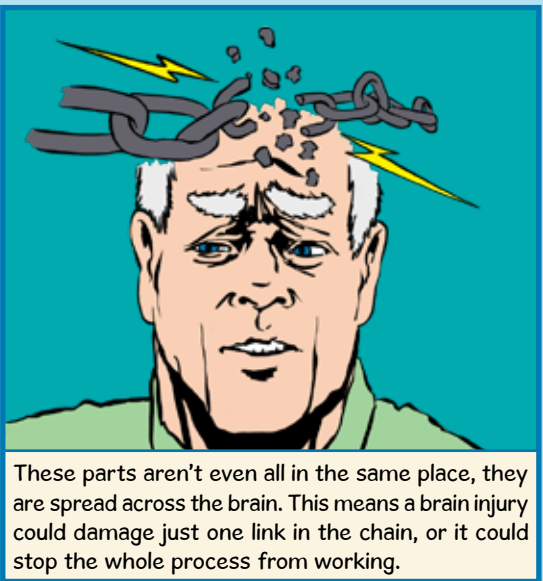
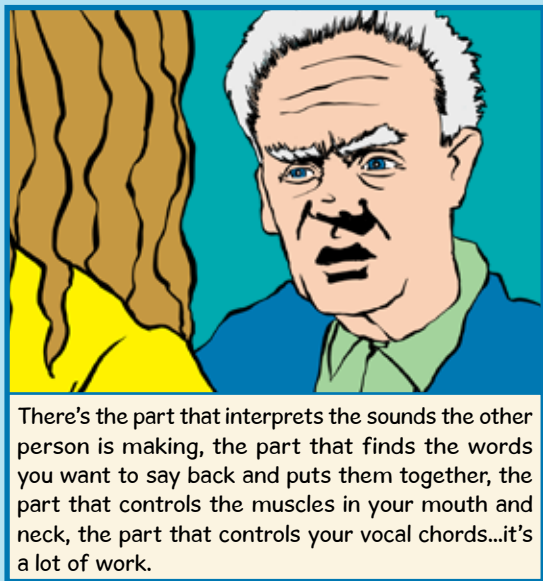
A brain injury to the parts of the brain responsible for emotion may take this awareness away again. We may lose the remote and with it the ability to control the levels of emotion we show and feel, and when and where we feel them.

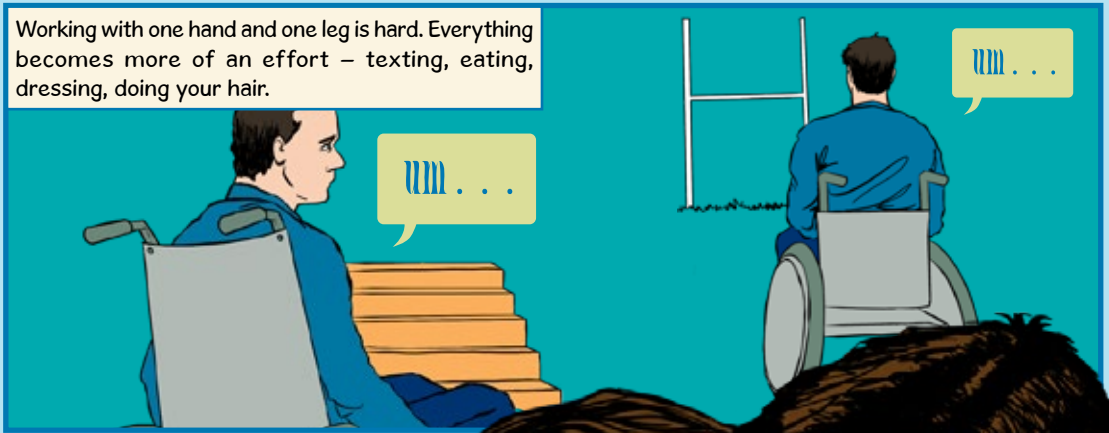
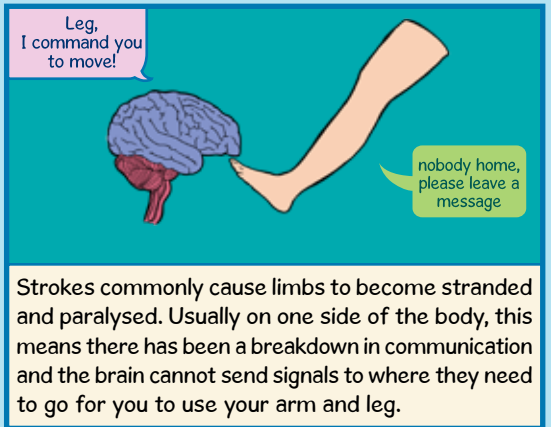
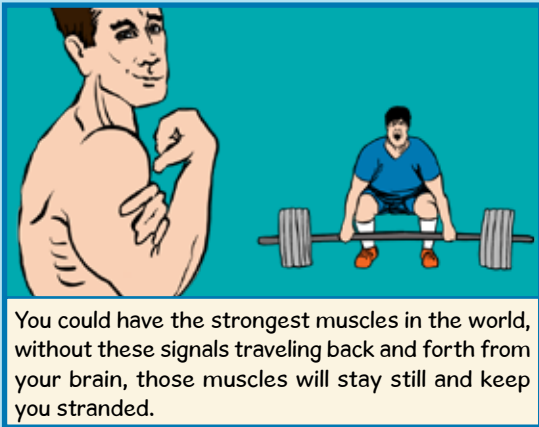


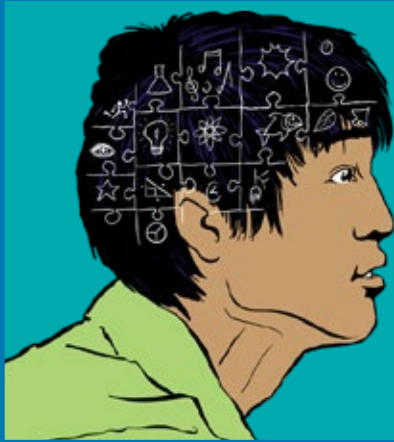
Just as a baby will cry if hungry, sleepy, or wet, it can happen that the brain gets stuck on one emotion that gets used in every situation. Perhaps anger. The brain can also get stuck at one level for all emotions. Perhaps everything is on loud, or silent.



The person with the brain injury may not be aware that they have lost their remote control. One particular emotion may just be their new reality. It may not seem unusual to them that they are angry all the time. They may not notice if they laugh at everything. They may not know it is strange to not feel any emotion at all. They cannot control this.







There are so many different types of memory. Short-term, long-term, working, muscle, verbal, visual, kinetic...we don't make memories just in one particular way.



Making a memory is a process that uses many different parts of the brain and follows different steps. So when someone has a brain injury, it's very likely that they will have trouble with their memory, because it is difficult to damage a part of the brain that is not linked to memory in some way.



If you can remember every word of a conversation with your best friend, but not the words to a Shakespearean sonnet, there's a good reason for that. The first thing you need to do to make a memory is pay attention.



Once you are focusing on a piece of information, then your brain starts to process and understand it. Here it makes the call on whether this information is important to you - is it something you need? Something you want to remember in the future?



If the answer is yes, your brain will retain the information, storing it and making it into a memory. Where it gets stored depends on how quickly you will need the information again. Long-term memories are stored in a different place from something you need again for tomorrow.



Lastly, there's the part of the brain that kicks in to help you recall: this is the act of searching for and dragging the information from its storage place and into the front of your mind.

Brain injury brings changes. These changes can be small and subtle, or they can be big and obvious. Sometimes the changes are only evident to the person with the brain injury. Sometimes they are so fundamental that everyone around them can see and feel the changes too.

Change doesn't just happen to the person with the brain injury. Change can happen for everyone close by: their family, friends, all of the people who know and love them.

When the changes are big and obvious, it can seem like the person you know and love has been taken over by some kind of alien being. It can seem like this brain injury has turned them into someone else.



It's hard when things change. Especially when the changes make things worse for a while. When the people around you are angry and sad a lot, it can sometimes feel like this is your fault. It is really important to know that this is not the case. They are not angry and sad because of you. They have not changed because of anything you did.

No one chooses to have a brain injury. No one chooses to get hurt and become a different person, but because the brain is so complicated, because it controls everything we do, think and feel, this is what can sometimes happen.

For some people, the changes only last for a little while. For others, they can be permanent. The brain cannot always make itself better. It might not be possible for it to go back to the way it was, to grow new neurons or mend broken synapses; we may need to try and find a way to live with the changes, to live with this new person.

If your family member has had a brain injury, it might feel in the beginning like the world has been turned upside down. Everything always in slow motion or at high speed, everyone focused on the person who got hurt or sick. Even as things begin to balance out, it may not feel like life is back to normal.

It can be easy to get lost in all of the worry and commotion, the new routines and endless appointments. With the focus always shining on the person with the brain injury, you may feel slightly hidden in the shadows, like you cannot ask for what you need, that they must come first.

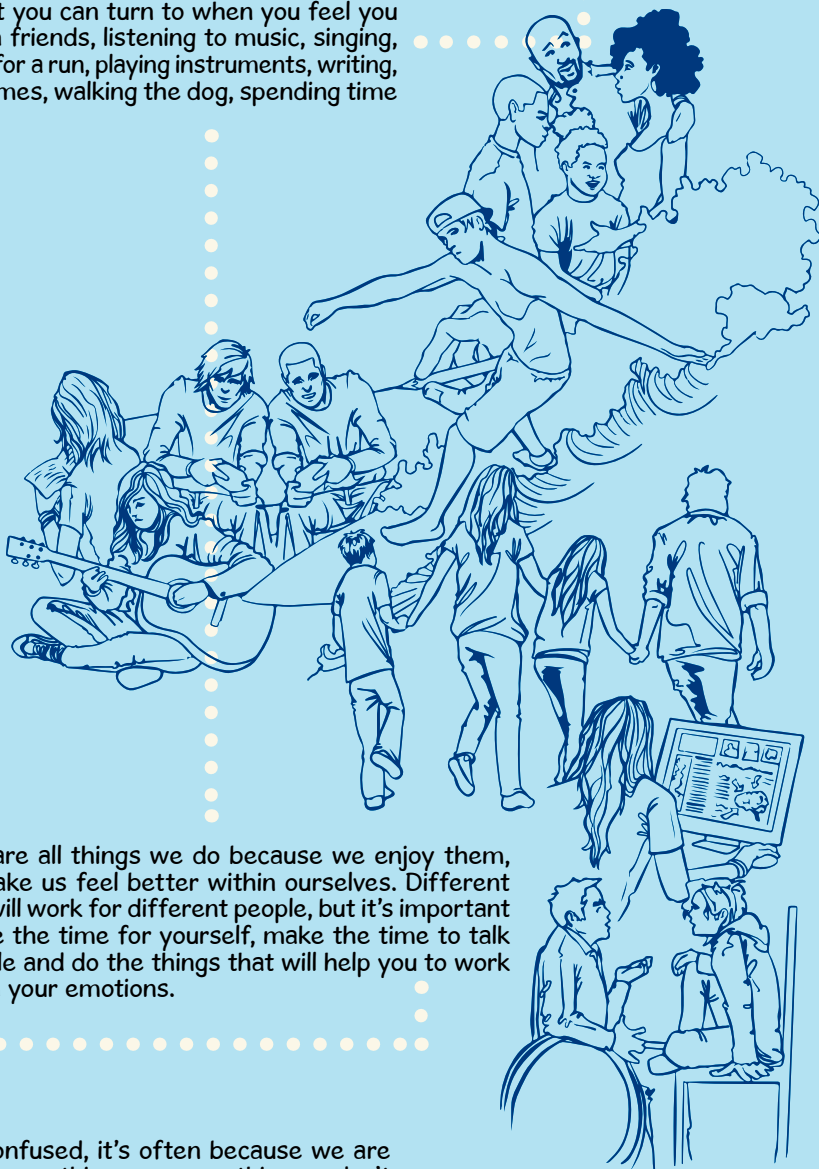
Your needs are important too, and it is absolutely ok to ask for them to be met. Everyone needs help sometimes, and everyone needs someone to talk to. Keeping things bottled up can make small worries and problems turn into big ones really quickly. Having a chat with someone - your friends, an adult you trust - helps the worries and problems to be manageable. It's easier to find a solution when you have someone on your side to help.



Emotions are tricky. They can be complicated and confusing. They can be overwhelming, it can be hard to know what to do with them. Emotions are also normal. Feeling and expressing them is a big part of what makes us who we are. It's how we experience and communicate with the world.

It's ok to laugh when we feel happy. It's ok to cry when we feel sad. It's ok to rant when we feel angry. It's ok to want a hug when we feel scared.

There are lots of safe ways you can express the emotions you are feeling. Looking after yourself is important and we all have different ways of doing that. It can help to make a list of all the activities and people that you can turn to when you feel you need them. Hanging out with friends, listening to music, singing, dancing, playing sports, going for a run, playing instruments, writing, reading, playing computer games, walking the dog, spending time with family.



These are all things we do because we enjoy them, they make us feel better within ourselves. Different things will work for different people, but it's important to make the time for yourself, make the time to talk to people and do the things that will help you to work through your emotions.

When we feel scared and confused, it's often because we are faced with the unknown, with something new, something we don't understand. Taking the time to get to know about brain injury, taking the time to get to know the changes, taking the time to get to understand why things are different - this will help you to look after yourself, as well as the people you love.



Brains are complicated, we pretty much have that message by now. However, they are also amazing, and infinitely resourceful within that complexity.



There's a lot you can do to help someone who has had a brain injury. Simple, practical things can make a world of difference to them and to you.



It seems an obvious place to start, but talk to the person with the brain injury. Try not to be afraid of the changes. Ask questions and help each other to understand.



Fatigue is a big thing. Not just feeling tired, but completely wiped out, can't do anything, fatigue. Be mindful of this, encourage rest and breaks as needed.



Remember sensory overload? If you want to talk, get rid of distractions. Minimise noise and let them focus just on you.



Take the pressure off. If someone cannot remember things, don't force it. There's lots that will help. Use noticeboards, sticky notes, diaries and notebooks. Write it all down.



Similarly, if you're out and about with someone who has memory problems, take photos and videos that you can watch back together. Try not to move their important stuff like keys and wallet - keep it all together in one place so they know where it is.



It can be a little scary and confusing talking to someone with language problems, but it doesn't have to be.



We say so much through our bodies, so let them speak for you more. Use facial expressions and gestures, move around and dance if it helps.. communication is more than words.



When you are speaking, do so slowly and clearly. Be prepared to repeat yourself if needed. Complement your words with drawings and pictures - they really do say so much.



Listen. Slow down. Give them time. Let them know it's ok to keep trying until they get it, and that it's ok to stop and come back to the words later.



Don't laugh. Sometimes people can come out with some funny things, saying the wrong words, swearing a lot, even gibberish. They can't help this, be understanding and compassionate.



Finally, try to be patient. It's hard. We move so quickly in this world and after a brain injury, people can't always keep up. This is ok. Slow down with them, it will help you both.



Some information that might help.

WEBSITES:

www.headway.ie

The website for Headway, filled with information about brain injury and Headway services.

<http://comics.tbi.washington.edu/home>

TBI InfoComics, a series of webcomics filled with information about the effects of brain injury.

<http://brainmadesimple.com/>

A great website about the brain written for non-neuroscientists.

<http://channel.nationalgeographic.com/brain-games/>

Brain Games on the National Geographic Channel has loads of short videos, games and episodes all about the brain and how it works.

FILMS:

Our Way - a short documentary film about living with brain injury made by Headway Cork in 2014. Available on the Headway youtube channel here: https://www.youtube.com/watch?v=g6N6_W-gpLw

The Crash Reel - a documentary about a young snowboarder named Kevin Pearce who suffered a traumatic brain injury. Available to buy on amazon.co.uk or to rent on Netflix DVD.

BOOKS:

He Never Liked Cake, Janna Leyde - a book written by a young woman whose father suffered a brain injury when she was a teenager. Available to buy on amazon.co.uk

Journey to the Brain - a colouring book aimed at teenagers, detailing the anatomy of the brain. Available for free download at <http://www.rcsi.ie/brainjourney>.

If you need to talk, we recommend that you try and talk to an adult you trust - like a parent, family member or teacher. If you don't feel comfortable doing this then you can call Childline or visit the sites below in confidence.

- Call Childline on 1800 66 66 66 or Text To Talk 50101
- Samaritans 116123
- www.teenline.ie or Call 1800 833 634
- www.spunout.ie
- www.reachout.com