



IDENTITY AND EMOTIONS AFTER ACQUIRED BRAIN INJURY

AND HOW TO HELP

INTRODUCTION

Acquired Brain Injury (ABI) is the term to describe an injury to the brain that you were not born with. ABI and recovery are experienced differently by everyone. The team at P.A.U.L For Brain Recovery want to support you during this difficult time and help you understand how an ABI may affect your life and how to manage the changes that occur. This booklet will specifically focus on changes to a person's identity and emotions.

After reading this booklet, we hope you have a better understanding of how brain injury can impact how you feel (your emotions) and how you see yourself (your identity) and how these can be managed with the support of health professionals, P.A.U.L For Brain Recovery and the wider community. The booklet can also be used to inform friends or family members of those affected by ABI.

YOU
are not
ALONE

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How and why can brain injury change my personality?

When we say personality we tend to mean the individual differences in how we think, feel and behave. There are certain areas of the brain that are most responsible for things we usually associate with personality - these are usually in the frontal lobe (behind your forehead and eyes), and right in the middle of our brain. Brain injury can cause subtle or quite pronounced changes in personality due to the changes in how the brain is structured or communicating.

A FEELING OF LOSS:

This can force us to adapt to a new form of ourselves that is different to the one before. A changing sense of identity can be very challenging and traumatic, and families may feel they have lost the person they once knew. This can be particularly difficult when you may not have any physical changes. Having suffered a brain injury is often a “hidden disability”.

Sometimes people describe managing these difficult circumstances as similar to going through a bereavement, and both the individual with the brain injury and their friends/family can experience it. This is sometimes described as an “ambiguous loss”, where the person may be physically there, but somehow different. Processing these emotions and changes can take time; there is no right or wrong way to adjust to or grieve the changes, and it is ok to experience these feelings.

Brain injury can also affect your confidence, self-esteem and how you may view yourself in relation to others. Your brain injury may have affected your ability to engage in activities you used to enjoy as part of a team, or has meant that you have lost some functional skills.

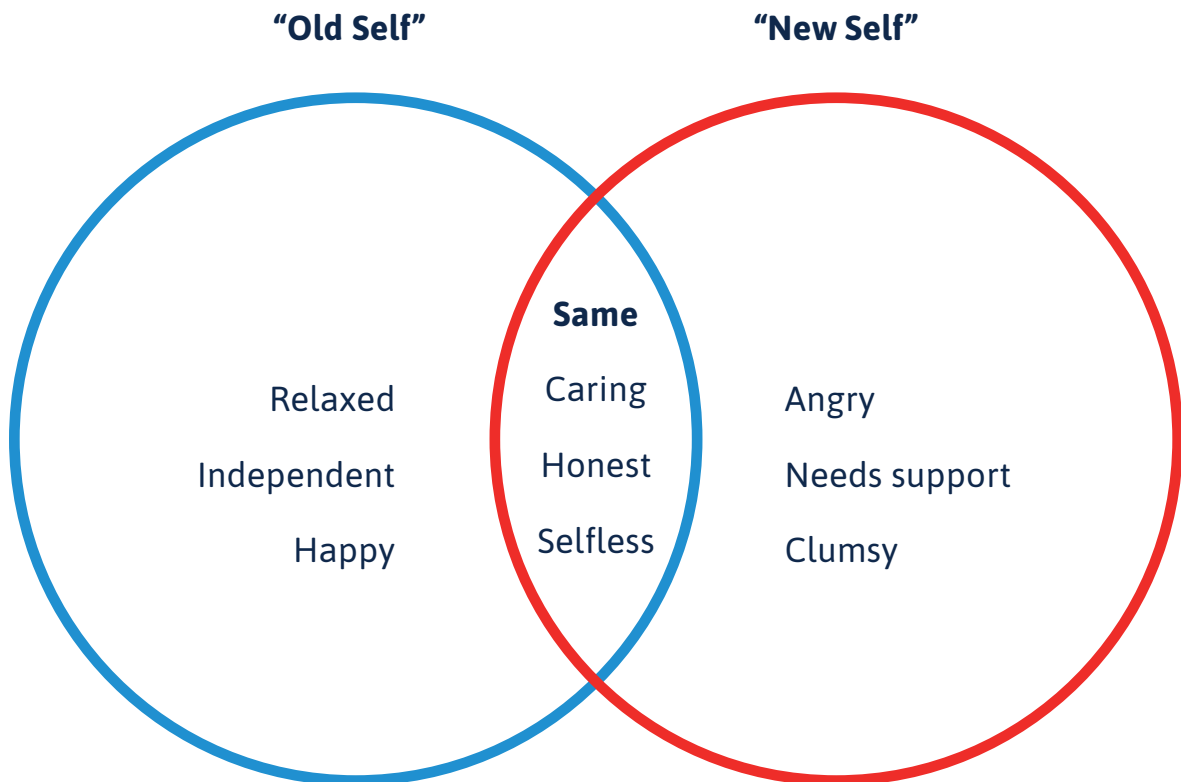
IMPULSIVITY:

After a brain injury, our executive functioning can be impacted. This is a group of mental skills that help us ignore distractions and manage controlling our impulsive thoughts/behaviours. When this is impacted it can lead to spontaneous and sometimes inappropriate behaviour. It may include acting without taking the time to think the decision through, struggling to manage finances, being over-familiar with strangers and sharing personal details easily. If you struggle with this, it can be helpful to self-monitor. Self-monitoring includes asking yourself questions such as: what are the pros and cons of this decision? Do I really want to do this? What will the outcome be?

How and why can brain injury change my personality?

LEARNING ABOUT YOUR 'OLD SELF' AND YOUR 'NEW SELF':

It is important to be aware of how you are feeling. You will likely experience a range of emotions as you come to terms with your injury and level of functioning and you may start to compare your “old self” to your “new self”. Although there may be many differences at first, looking at what overlaps and what values are most important to you (for example, family and friends) can help you to identify what you still share with your “old self”.



Why and how can brain injury change my emotions?

Suffering a brain injury impacts everyone differently, and everyone's experience is unique. Some brain injuries may cause damage to certain parts of the brain which may be involved in regulating emotions, how your brain would usually calm itself. This can mean that some people may experience a lot of emotional changes.

After a brain injury, it is normal for behaviour and emotions to change even if this part of your brain wasn't damaged.

YOU MAY EXPERIENCE FEELING:

HEIGHTENED OR FLATTENED EMOTIONS – This is where your emotional responses may be increased or decreased in response to events, becoming more or less sensitive. Some people describe it as if their emotions have been “dialled up or down”.

EMOTIONAL LABILITY – This is where your mood may rapidly change and be expressed very vividly. It is important to remember that these outbursts may not have any relationship to how you are feeling (you may cry without feeling sad, laugh when there isn't any humour) and this usually cannot be controlled.

FRUSTRATION – This could be having a “shorter fuse” than usual, or being more irritable than you used to be. This is very common after brain injury and can be difficult to manage. You may also express your frustration differently than usual, such as yelling, swearing or even become physical. This could be due to finding tasks more difficult than usual, the nature of your injury, or other factors such as pain or fatigue. After a brain injury your body is trying to manage much more than ever before. Try to remain patient with yourself.



Ways to help you manage your own behavioural changes

ANXIETY – You may notice worrying more than usual or find things that didn't affect you before suddenly do now. You may even experience feeling anxious without knowing why. Anxiety is part of our normal evolutionary “fight or flight” response, which exists to protect us from danger, and it can have a physical effect.

You might notice:

- Increased heart rate
- Sweating
- Dizziness
- Muscle tension



Although these can be uncomfortable feelings, anxiety is not dangerous.

LOW MOOD – A lot of people report feeling sad and low after a brain injury. You may become more withdrawn, feel hopeless and lose interest in things you used to enjoy. You might feel guilty about having negative thoughts, however, it is a completely natural response to feel grief, shock, fear and sadness after something as life-changing as brain injury. It is important to remind yourself that these feelings are normal, they will ease, and it is not your fault.

THERE ARE SEVERAL FACTORS WHICH ALSO CONTRIBUTE TO THESE CHANGES IN EMOTIONS OTHER THAN THE BRAIN INJURY ITSELF

You may be feeling this way as you learn to adjust to your life now with a brain injury and any temporary or lasting disabilities. You may be feeling misunderstood, or experience difficulty concentrating or remembering, which can lead to frustration. How we feel impacts on how we think, and therefore behave. Similarly, how we think can impact how we feel.

People often report feeling much stronger emotions than they did before and find they are easily triggered. It can also be difficult for people to recognise their progress in recovery and rehabilitation, and that can intensify these feelings.

Ways to help you manage your own emotions

NAME THE EMOTION YOU'RE EXPERIENCING

– Identifying your feelings can be a helpful way to communicate with your family and loved ones exactly how you are feeling if you struggle to express your emotions. It may be helpful if they also do the same so there is no misinterpretation. This may be as simple as saying “I am feeling sad” or “I’m frustrated”.



PLAN – When we experience heightened emotions, our ability to use the logical part of our brain decreases and we struggle to make sense of things. It can be a good idea to consider how to manage when you are feeling certain ways by preparing an emotional coping plan. Some people find it helpful to think of a traffic light system, for example, green when they are managing well, amber when they may be struggling slightly and red when they need support. Plan what you can do at each of these stages. It can be helpful to have a plan written out so you can follow it when you are feeling high levels of emotion.



For example, when you begin to feel frustrated you may plan to go to a quiet area (e.g. a spare room or outside) and listen to some calming music, or complete one of the strategies discussed later in this booklet.

EXERCISE – This can be a helpful way of managing some of the difficult feelings you may be experiencing. Make sure you speak to your healthcare professionals about engaging in any physical activity. Going for a daily walk or swimming are good examples of gentle activity, if you are able to.



Ways to help you manage your own emotions

ACTIVITY SCHEDULING – When you're feeling low in mood, you tend to be less active than usual and you might stop doing things that you enjoy altogether. This can be a vicious circle and make you feel even worse. Scheduling things you enjoy that give you a sense of pleasure can really help improve your mood. This may be going for a dog walk, taking a bubble bath or reading a book. However, it is important to monitor your level of fatigue as well to make sure you are not trying to do much.



POSITIVE EVENTS – It may be helpful to make a diary of positive moments; this can be written or as pictures. It can be easy to forget all the little things that happen that are positive or bring us joy and documenting them in some way can help.



PEER SUPPORT – Remember that the types of problems you face can be quite complex and it is not uncommon for people in your situation to feel isolated or to feel that other people do not understand what you are going through. It may be helpful for you to have contact with groups and organisations that support people with similar conditions. Groups such as P.A.U.L for Brain Recovery can offer support to people in your situation. You may find it beneficial to link up with others who have experienced something similar to you, or even find value in helping others. These support groups can be really helpful in maintaining your social connections and engaging you in meaningful activities.



Ways to help you manage your own emotions

RELAXATION TECHNIQUES

The strategies below are ways to help you relax. You may find them helpful when feeling overwhelmed or anxious. There are also many guides and apps which can help you with these techniques.

FOCUS (THE 54321 TECHNIQUE):

5 Things you can SEE



4 Things you can HEAR



3 Things you can TOUCH or FEEL



2 Things you can SMELL or that you LIKE the smell of



TAKE **1** big **BREATH** in



Ways to help you manage your own emotions

RELAXED BREATHING:

Make sure you are in a **comfortable position**, whether that's sitting or lying down. You can also close your eyes if you feel comfortable. Try to breathe **in through your nose** and **out through your mouth**.

Breathe in to a count of 4, pause for a moment, and breathe out to a count of 4.

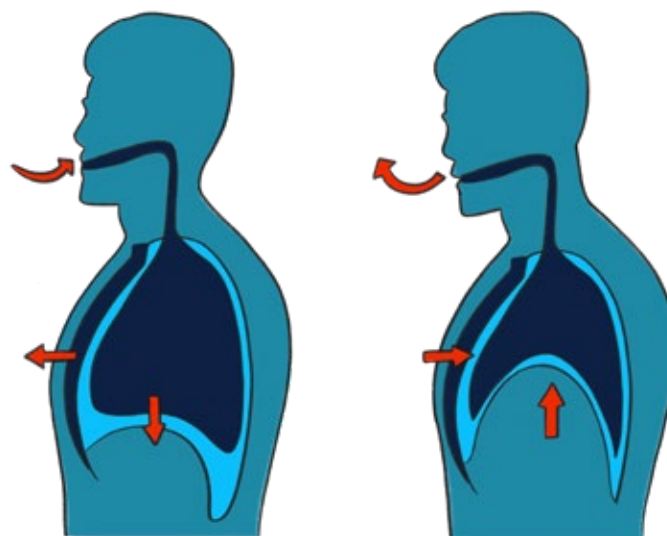
Breathe in...2...3...4...Hold... 1...Out...2...3...4.....

If possible, **focus your breathing lower down in your belly** and not high up in your chest. Check this by putting your hand on your stomach and seeing if it moves when you breathe in.

Keep your breaths slow, smooth, steady and continuous.

Try breathing in this way for **a few minutes at a time** – it may take some time for the balance to be restored. If you can, **aim for 5-10 minutes** of relaxed breathing.

Remember to practice! Although it may seem easy – relaxed breathing may take some time to get the hang of. Try to practice three times a day if possible.



Ways to help you manage your own emotions

PROGRESSIVE MUSCLE RELAXATION

This is a simple but very effective relaxation technique you can learn to help alleviate tension and stress. The majority of people find that it is best for them to hold the tension in their muscles for between 5 and 10 seconds and you can repeat tensing specific muscles if you feel you need to. If you feel any pain or discomfort when you target a specific muscle group, feel free to leave that step out – you should feel as comfortable as possible at all times.

GETTING STARTED: Make sure you are comfortable, whether that's sitting in a chair or lying down. A quiet environment will also help this exercise so you can focus fully on yourself.

EXERCISE:

Bring your attention to different parts of your body, one after the other. Go through the sequence at least twice for each body part.

Tense: As you breathe in, tense that body part

Hold: Hold your breath and the tension for a few moments

Relax: Slowly let the tension go as you breathe out

RECOMMENDED SEQUENCE

Toes and feet – curl your toes down

Calves – turn your toes upwards towards your knees

Thighs – stretch your legs out fully

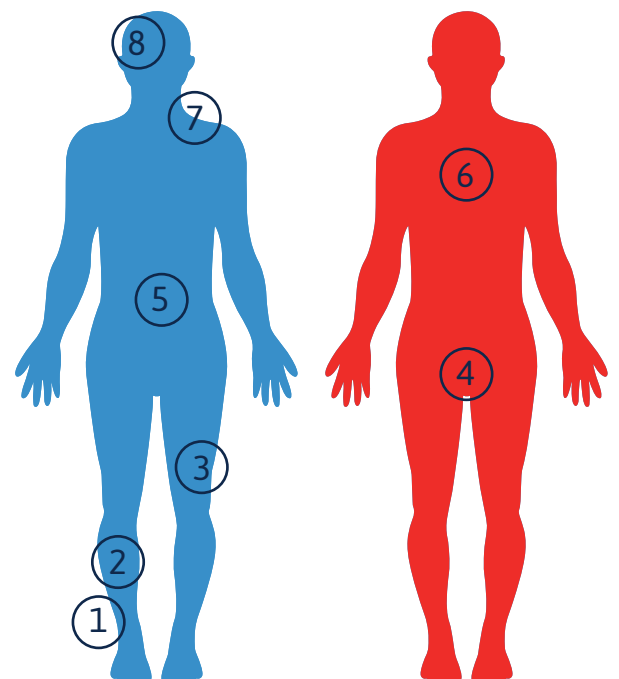
Buttocks – clench your buttocks

Stomach – try to pull your belly button to your spine

Back – arch your body forward

Shoulders & neck – lift shoulders up together

Face – scrunch your face up



Sleep Hygiene Tips

Making sure that you get good-quality sleep is important in brain injury recovery and can give your brain better resources to help cope with changes in your emotions and identity. The following are tips on how to get effective sleep.

CREATE A SLEEP SCHEDULE AND STICK TO IT

Pick a bedtime and a wake-time and try to stick to them as much as possible. This is to get your body used to having consistency and routine. Make small changes slowly so that your body has an easier time adjusting.



BEDTIME ROUTINE

Create a relaxing routine you can do right before you go to sleep. Try to give yourself one to one-and-a-half hours to wind down before going to sleep. Make sure this doesn't involve bright lights or electronic devices such as laptops or phones. Having a bath, reading a book or listening to an audio-book in another room are good examples of things you can do.



GIVE YOURSELF A COMFORTABLE AND RELAXING SLEEP ENVIRONMENT

Make sure you have comfortable bedding, that your room is not too hot or cold and that it is a nice, quiet and dark environment for you.

BED = SLEEP

Remove any work materials, computers and other electronic devices from your room. Try to use your bed only for sleep, sex and getting dressed, in order to strengthen the association between bed and sleep. If you can't fall asleep after about 20 minutes, get out of bed, move to a different room and try to do a quiet, relaxing activity such as reading until you feel tired again.



Sleep Hygiene Tips

THINGS TO AVOID WHEN TRYING TO GET TO SLEEP!

TRY TO AVOID ANY PRODUCTS

CONTAINING CAFFEINE (tea, coffee, chocolate, cocoa, soft drinks etc.) for four to six hours before bedtime. Alcohol, heavy, spicy or sugary foods and nicotine in the four to six hours before bed can also affect your ability to stay asleep.



NAPPING – You may need to rest more throughout the day after your brain injury. However, if you are having trouble sleeping at night it may be due to this. Try other methods of getting an effective rest, such as listening to calm, quiet music or watching nature if you are struggling to sleep at night.



GOING TO BED TOO HUNGRY OR TOO FULL

– Try a light snack. Warm milk and foods high in the amino acid tryptophan, such as bananas, may help you sleep.



CLOCK-WATCHING AT NIGHT – Looking at the clock when you wake in the middle of the night can make you feel anxious about not falling back to sleep. We make unhelpful judgements about the time when we check, which makes us more worried or frustrated, and this can be made worse by brain injury.

TRYING TO MAKE YOURSELF GO TO SLEEP IF YOU'RE NOT SLEEPY – This will only make you more alert. Try to do something such as sitting in a dark room until you feel sleepy.

Try removing the clock from your bedroom. If you need to wake to an alarm, face the clock away from you, or cover it. If you use your phone, try putting it face-down at the opposite side of the room.

How friends and family can help

REMAIN CALM and avoid acting emotionally if your loved one is distressed.

WHEN NECESSARY, TRY TO MOVE TO A QUIET/CALM AREA to help them regain their control. Quieter, calmer environments reduce the amount of information your loved one has to process, reducing the demands on their brain, making it easier to focus on and process the emotions.

ACKNOWLEDGE THEIR FEELINGS and provide a space to talk about them. It may also be helpful for you to reflect the emotion you are noticing, as your loved one may struggle to identify their own feelings.

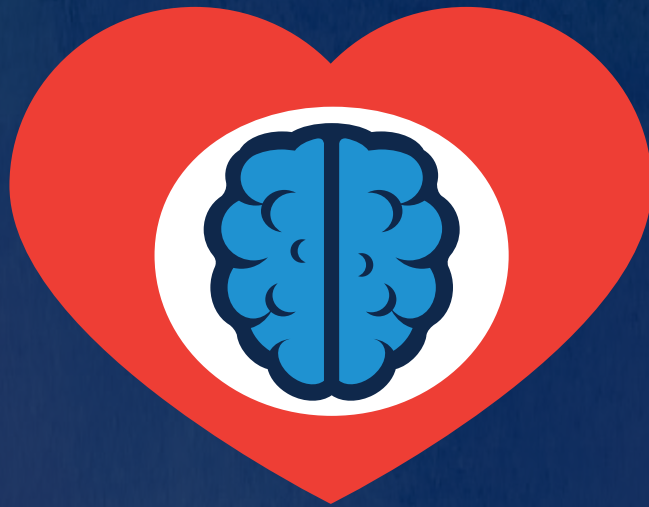
TRY TO OFFER A GENTLE DISTRACTION with a task or conversation if they are becoming increasingly frustrated or upset.

ENGAGE YOUR LOVED ONE IN ACTIVITIES THEY USED TO DO if possible, or make alterations where possible, to help them connect with their sense of self, finding enjoyment in the things they used to do.

MODEL THE EMOTION YOU THINK WOULD BE HELPFUL for your loved one. It is easiest to change your emotions when you see others are displaying a different emotion as we tend to mirror the feelings of those around us. If your loved one is displaying frustration or anxiety, for example, show calmness yourself, by taking deep breaths and using open body language to help them copy this.

TRY TO BE PATIENT remember, they did not ask for this injury to happen. Suffering a brain injury may be challenging and it is important to remember they have to navigate the world very differently than they used to and this can be scary. They may not realise they are acting differently and although you may not be able to see, their brain injury is impacting their functioning.

This booklet aims to develop your understanding of changes to identity and emotions after brain injury, helping you identify difficulties and provide initial strategies. You may find it helpful to explore particular areas in more detail. P.A.U.L For Brain Recovery has further literature on some of the elements discussed here and you can also talk to the team personally. Alternatively you may find it helpful to seek referrals to specific healthcare services.



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