

Module 1: Understanding Traumatic Brain Injury – The impact on emotions, thinking and behaviours

Welcome and Module Overview

Welcome to the Carers' Way Ahead program for families of people with Traumatic Brain Injury. This is your first Module summary. Well done for making the time to learn new ways to help your family member with brain injury. In this module you met two families. Their stories will be used to explain some of the techniques involved in helping a family member with traumatic brain injury, especially when they have challenging behaviours. Of course, your own experience with your family member will be very personal and may be different to the families in the program, but we hope you can relate to some of their experiences.

Here is an overview of the seven modules of this program. The first two modules are educational and need to be completed first. Then you can choose which of the five modules you would like to complete.

Psychoeducation Modules:

- | | |
|-----------------|--|
| Module 1 | Understanding the impact of brain injury on thoughts, feelings and behaviour |
| Module 2 | The ABCs of Challenging Behaviour |

Challenging Behaviours & Self-Care Modules

- **Low Motivation and Drive**
- **Irritability and Aggression**
- **Difficulties in Social Situations**
- **Acting Without Thinking**
- **Taking Care of Yourself**

Program Overview

This program includes:

- **A module summary (like this one):** includes the important information taught in the module and key strategies and skills to use with your family.
- Extra resources on topics such as links to websites and information about available services.
- Frequently asked questions about the program

Who is this program for?

This program is designed for families and carers of people who have had a traumatic brain injury who experience difficulties coping with their family member's challenging behaviour. This includes:

- People with brain injury who get irritable and act aggressively
- People with brain injury who have difficulty getting going and show low motivation
- People with brain injury who have difficulties in social situations
- People with brain injury who act without thinking
- Families members who are experiencing stress and anxiety

Topics covered in this summary?

Here is a list of the topics we will cover in this Summary. Tick these off as you go:

1. Ann's Story: John
 - a. Irritability and aggression after brain injury
2. Gerry's Story: Sandra
 - a. Social difficulties after brain injury
3. The "Manager of the Brain" – the Executive Functions
 - a. Planning and Organising
 - b. Controlling Behaviour
 - c. Regulating Feelings
 - d. Problem Solving
4. What "thinking problems" and challenging behaviours happen after brain injury?
 - a. Lack of Insight or Awareness
 - b. Impulsive Behaviour
 - c. Lack of Flexibility
 - d. Difficulty Regulating Emotions
 - e. Poorer Social Skills
 - f. Self-Centeredness
 - g. Poor Motivation
5. Your Checklist
6. Summary

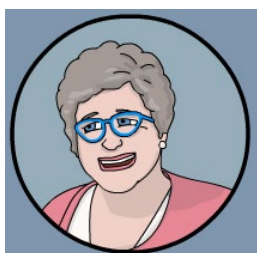
1. Ann's Story: John



John is a 22 year-old man who got his brain injury when we was out in the city with his mates, and was hit in the head by a stranger. He fell backwards and hit his head on the street. John gets very irritable and aggressive since his accident and has difficulty controlling his temper. Below is a list of challenging behaviours that John shows. Tick the boxes of the ones that your family member has difficulties with:

- Swearing
- Throwing things
- Yelling
- Wanting alcohol or cigarettes
- Demanding things
- Easy to lose temper
- Difficulty calming down

2. Gerry's Story: Sandra

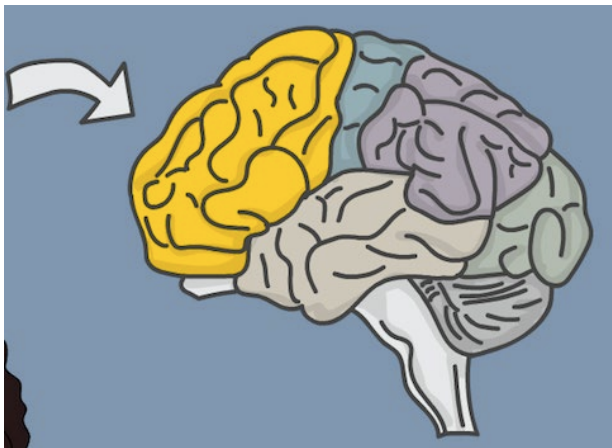


Sandra is a 55 year-old woman who lives in the country with her husband, Gerry. Sandra obtained a brain injury when she was in a car accident while driving back from their son's house one evening. Gerry was driving the car. While Sandra recovered from many of her injuries, she continues to show some difficulties in social situations. She often says rude or embarrassing things, and sometimes she doesn't make sense. She also gets frustrated easily when people don't understand her. Below is a list of challenging behaviours that Sandra shows, especially in social situations. More have been added. Please tick the boxes of the challenging behaviours that your family member has difficulties with:

- Saying things in a jumbled way – they don't make sense
- Saying rude or hurtful things
- Being blunt or too direct
- Talking about themselves a lot
- Not taking turns in conversation
- Not noticing other people's body language or facial expressions (for example, when people are bored or hurt).

3. The “Manager of the Brain” – The Executive Functions

Many of the challenging behaviours we see as a result of brain injury happen because of damage to certain parts of the brain, including the frontal lobes (at the front of the brain). These parts of the brain manage the “executive functions” which help us to control what we say and do as well as our emotions.



Planning and Organising

This involves deciding what we want to do and when we want to do it. It also involves organizing and prioritizing information from different people or places. An example of this is when Sandra wants to go and visit her son, she needs to plan when she is going to go (will her son be home?), how she is going to get there (can her husband drive her, or will she drive herself?) and what she might need to take with her (phone, wallet, keys, food for lunch etc.).

Controlling Behaviour

This involves doing our best to change our behaviour when we are in different situations. We need to be flexible with our behaviour depending on the situation. Also, we need to be able to learn from mistakes or feedback. For example, John would need to change the way he speaks and acts when he is with his brothers compared with when he is at a doctor's appointment or a job interview.

Regulating Feelings

This involves being able to control how we react to others and how we show what we are feeling. For example, if John is told by his supervisor that he has made a mistake, he needs to stay calm even though he is feeling angry and upset. If John wasn't able to control his feelings he might yell and scream at his boss in front of the whole office, and therefore risk losing his job.

Another problem with feelings, is that some people with brain injury are not being very good at reading how other people are feeling. This means they may not know when the other person is happy or angry or sad. This makes it very difficult to be sympathetic, or to know how to react.

Problem Solving

This involves thinking through a problem, working out the best way to solve it and then choosing the best option. For example, when Sandra is trying to do cook something for her family, but can't find the recipe, she might solve the problem by looking it up on the internet.

4. What “thinking problems” and challenging behaviours happen after brain injury?

When the frontal lobes of the brain are damaged, our actions and behaviour are affected. Also, when people with brain injury have to do things that are new or when they are tired, stressed or worried, these become very difficult. People with brain injury may show difficulties with:

Lack of Insight and Awareness

This involves knowing what things you can and can't do. A lot of the time, people with brain injury are less aware of their own behaviour and its impact on others. It can be very difficult for them to learn how to change.

For example, Gerry said that Sandra was not aware that her comments are rude or hurtful to others. Even when Gerry tells Sandra that she has said something rude or hurtful, she doesn't change her behaviour next time. Sandra knows what she has said was wrong or rude, but she still can't seem to change.

Impulsive Behaviour (acting without thinking)

This involves having an idea or thought and then acting on it without thinking through the consequences. The person may find it difficult to keep their thoughts to themselves and so they end up blurting out whatever is on their mind. They can even say inappropriate things that they never would have said before their injury. Even though a person with a brain injury may seem to know what they should do, the damage to their brain stops them from doing it.

Gerry gave the example of Sandra spending all her money on new shoes. She already has lots of shoes, and now doesn't have enough money to buy more important and needed things.

Ann gave the example of John yelling out hurtful or abusive things to his brothers when they do something that he doesn't like, or when he can't do what he wants. Because his brain is injured, he cannot think through the consequences of yelling at his brothers.

Inflexibility

Flexibility involves being able to change your thinking when you need to. If something in the environment changes, you might need to change your plans too. With a brain injury, people can become inflexible.

For example, Sandra and Gerry enjoy going for a walk in the afternoons. But when it is raining, they need to change their plans. When Gerry suggests going to the movies instead, Sandra gets upset because in her mind she had planned to go walking.

Difficulty regulating feelings

People with brain injury often get upset quickly and are sometimes not very patient when things change. Regulating feelings can be difficult after brain injury because the damaged brain area can increase the strength of the emotion and result in the person doing things based on their feelings. So people with brain injury will often respond to unexpected, mildly unpleasant things (e.g., a loud noise) with a much bigger reaction than they did before their injury.

Lower Frustration Tolerance

People with brain injury also seem to get frustrated very easily and have, what is called, "lower frustration tolerance". They may get angry more quickly or react with stronger emotions to events, which can be completely over the top. They also then have more difficulty calming down once they are upset.



John gets angry with his brothers for being loud when they are playing in the backyard and John is trying to watch TV. His brain injury makes the situation feel more frustrating than before his injury and his anger seems to go from 0 to 100 very quickly. John's brain injury also makes it difficult for him to control his reactions when he gets angry. For example, when John heard his brothers playing

loudly in the backyard, he reacted impulsively and strongly by yelling and throwing something at them.

Poor Social Skills

People with brain injury have difficulty knowing how to act around other people in different types of situations. The executive functions help us to control what we say and do right now, so that we can control what happens later. They also help us to know that we need to speak to our boss or supervisor differently from how we speak to our partner or friends.

Sandra often mentions personal or awkward things about others in front of them, which causes embarrassment for other people. She has difficulty “holding her tongue” and blurts out things without thinking, even though it hurts her friends or family. For example, Sandra told her daughter-in-law that her new haircut makes her look old, even though it was hurtful to say.

Problems ‘reading’ other people can also make it hard in social situations. So when someone else is upset and showing it, the person with the brain injury may still not realise that is how they are feeling.

In Sandra’s case, even if her daughter-in-law looks upset about the remark she made, Sandra may not be able to pick up that her daughter-in-law is upset. Sandra then gets quite upset and confused when her friends and family start to avoid spending time with her because she does not understand what she had done wrong.

Self-Centeredness

This involves believing that other people’s choices and actions need to revolve around “me”. People with brain injury can often seem very demanding and fail to see other people’s points of view, but actually it’s the injured brain that is the problem.

John thinks “only my choice of TV show is right” rather than thinking about whether other people might want to watch their choice of show and whether it may also be good.

Poor initiation, motivation and drive

Sometimes challenging behaviours can be NOT doing something. For example, the person isn’t motivated to do something or they don’t do things even when they say they want to. This can be very frustrating and challenging for family members.

When thinking about how we do things and why we do things, we can think about starting a car... we need 3 things to get a car started:



1. We have an engine, which is our “**drive**”. This is our ability to physically do something such as walking.
2. We have a key, which is our “**motivation**”. In order to start the engine we have to have the desire or motivation to start it.
3. Once we decide to start the engine, we have to turn the key, which sparks the ignition. This is known as our “**initiation**”. Even if we are motivated and have an engine that works, we need to create the spark to get it going.

So, after brain injury, you can have problems with motivation, initiation or the drive itself.

Your Checklist

Your tasks to do following this module are:

- Review Module 1 again
- Re-read and print out this module summary (it won't take long!)
- Recognise the executive functions that are affected following brain injury
- Recognise the “thinking difficulties” and challenging behaviours that occur after brain injury
- Understand why “thinking difficulties” and challenging behaviours occur after brain injury
- Explore the frequently asked questions and extra resources sections on the website
- Reward yourself for completing Module 1.

Summary

Congratulations on completing the first module of the This Way Ahead program. In this summary we discussed the Executive Functions (“manager of the brain”) and what they do. We also discussed the thinking difficulties and challenging behaviours that occur after brain injury and why these happen.

Great work, you have now completed the first module. Remember, you can come back whenever you like and re-read Module 1. In fact, we would encourage you to re-read it at least one more time this week.

We would like you to come back and check out Module 2. See you then!