

YOUR GUIDE TO

# Managing Behaviour after ABI

arbias

BrainLink



*Managing Behaviour After ABI* is part of a series of information products about acquired brain injury (ABI) produced by a joint committee of brain injury organisations with the support and assistance of the Department of Human Services, Victoria.

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# CONTENTS

<b>Behaviour Change After ABI</b>	<b>4</b>
<b>What Causes Challenging Behaviour?</b>	<b>6</b>
Brain injury	6
Environment	7
Personal Factors	7
<b>About Behaviour Management</b>	<b>8</b>
Managing, not fixing, behaviour	8
Structure	8
Consistency	9
Add positives	9
Seek assistance	9
<b>Suggestions for Managing Challenging Behaviours</b>	<b>10</b>
Dealing with aggression	10
Dealing with socially inappropriate behaviour	12
Dealing with inappropriate sexual behaviour	14
Dealing with reduced drive and initiation	16
<b>Conclusion</b>	<b>18</b>

# Behaviour change after ABI

**A**cquired brain injury (ABI) occurs when the brain becomes damaged through trauma (falls, car accidents, fights), a stroke, infection, a tumour, lack of oxygen to the brain (cardiac arrest or near drowning), through drug and alcohol abuse, or through a degenerative neurological disease (Parkinsons, Alzheimer's).

Changes to a person's behaviour are very common after ABI. These range from subtle changes, such as talking too much, to markedly altered behaviour, such as physical aggression.

Challenging behaviour can emerge or reappear at times of stress or transition. For example, people with brain injury and their families often imagine that life will return to normal when they come home from hospital or rehabilitation. While going home sometimes settles behaviour, many families report that behavioural issues become worse. There are many reasons why:

- Loss of routine and purpose after rehabilitation
- Increased stresses, such as changed finances and lifestyle adjustments
- Worry and depression
- Rising frustration as difficulties continue to surface

The amount of control someone with ABI has over their behaviour varies greatly from person to person. Some people exhibit the same kind of behavioural issues, no matter where they are or who they are with. Others are able to keep themselves in check with friends, their boss or people down the street, but "lose it" when they get home. Sometimes those closest to a person with an ABI bear the brunt of their anger and frustration.

This booklet provides introductory information, real-life case studies and suggestions for managing challenging behaviour.

Behaviour may be considered “challenging” when it occurs at the wrong time or place, causes distress, gets people into trouble, is against the rules, or limits opportunities.

The most common types of challenging behaviour include:

- **Verbal aggression** – swearing in front of the boss, shouting, threats
- **Physical aggression** – pushing, hitting, throwing objects, scratching
- **Inappropriate sexual behaviour** – sexual comments to a co-worker, touching, masturbation in public
- **Repetitive behaviours** – asking questions repeatedly, doing the same action over and over
- **Wandering** – leaving home and getting lost
- **Inappropriate social behaviours** – refusing to shower or take medication, demanding behaviour, failing to follow rules
- **Risk-taking behaviour** – not obeying road safety rules, excessive use of alcohol or drugs, arguing with the “tough” guy down at the pub
- **Reduced drive or difficulty initiating activities** – staying in bed most of the day, needing prompts to complete tasks

# What causes challenging behaviour?

Challenging behaviour after ABI is usually the result of a complex combination of factors that relate to an individual's brain injury, their environment and personal factors.

## Brain injury

Injury to the brain can cause physical, emotional and cognitive (thinking) changes that influence behaviour.

**Physical problems:** Problems with muscle weakness and coordination can lead to frustration and aggression if the person has no strategies to compensate.

**Emotional control:** After ABI, mood swings can occur and even trivial events may trigger extreme reactions.

**Memory problems:** Repetitive questions are common, and aggression can occur when the person struggles to recall information or to find something.

**Impulse control:** A person with ABI may say and do inappropriate things without thinking.

**Initiation:** A lack of 'get up and go', difficulty generating ideas, making plans and following through may occur. For example, despite being bored and wanting to do something, the person stays at home doing nothing.

**Lack of insight:** The person may deny having any significant problems, or acknowledge some problems, but have reduced awareness of their impact on others, daily life and future plans. They may blame their problems on others, refuse useful assistance, or insist that they are fine to return to work, to drive a car etc.

## Environment

Environmental factors, such as noise, overcrowding, rushing, or too many things happening at once can trigger challenging behaviour in a person with ABI.

**Inappropriate settings:** Challenging behaviours are more likely to occur when people are living in a place that doesn't suit them. For example, a young person living in an aged-care home.

**Inappropriate activities:** Lack of meaningful activities, or activities not suited to a person's interests, can lead to boredom or frustration.

**Actions of others:** Arguing with the person, giving in to angry demands, or paying lots of attention to inappropriate actions, can make the behaviour worse.

## Personal Factors

How someone reacts to life after brain injury will depend on their personality, resilience and coping skills. Some personality traits may become more prominent. For example, a person who had a short fuse before their brain injury may have temper-control problems after ABI.

**Psychological or psychiatric conditions:** Depression, anxiety, grief and frustration over loss of one's independence and freedom can all contribute to challenging behaviour.

**General health:** Illness, pain, or a bad night's sleep can lead to uncharacteristic conduct.

**Medication:** Side effects of medication, lack of appropriate medication, alcohol and other drugs, can all affect behaviour.

# About behaviour management

## Managing, not fixing, behaviour

The key to effective behaviour management after ABI is to manage challenging behaviour, rather than try to fix it.

A person with ABI is often totally unaware of the difficulties they cause others. Even if they do understand the impact of their behaviour, they may no longer have the ability to change or control it.

It is the people living and working with the person who are most able to adapt or change the way they do things to manage situations effectively.

*Peter is a young, married man who injured his brain in a fall. After returning from the rehabilitation hospital, his wife, Sue, began to notice how Peter would get angry with their toddler in the evenings. Peter was an active father before the injury and it had been his job to bathe and ready their son for bed while Sue cooked dinner.*

*Initially, Sue hoped there would be a way to “fix” Peter, but over time she realised it was easier to make changes to her own routine. She could see that Peter was not able to cope with a tired, cranky three year-old when he, himself, was tired. She reorganised her time to prepare dinner earlier in the day, freeing herself for the bedtime routine. Peter took over dressing their son in the mornings, when he felt more alert and energised.*

## Structure

Positive changes can be made by compensating for the part of the brain that has been damaged. For example, frontal lobe damage often leads to difficulties with organisation and planning. To assist with this problem, families or friends can provide the structure that the person is no longer able to provide for themselves.

Try developing a weekly routine that involves as little change as possible so the person can begin to anticipate what happens next and what is expected of them. The more severe the brain injury, the more structure is required.

## Consistency

Try to ensure as much consistency as possible in how things are managed by family, friends and carers. The best results come from a team approach, with everyone working in the same direction, not against each other.

## Add positives

Outcomes tend to be better when positive things, such as favourite foods and outings, are added to a situation in spite of challenging behaviour. Withdrawing positives in a punitive way tends to lead to more depression, anger and frustration.

## Seek assistance

Not surprisingly, challenging behaviour can often lead to isolation and a lack of support and understanding for people with brain injury and their families. This is particularly so when the behaviours are 'invisible' to people outside the home. Many families also struggle to come to terms with changes in their family member, and the adjustments ABI demands of their own lives and personal relationships.

It is very important to seek assistance from as many sources as possible to manage stress and avoid burn-out. Sources might include other family members, friends, health-care workers, carer-support groups and anyone who can help with activities and respite care.

## 5 principles for effective behaviour management

- **Manage** day-to-day behaviour, rather than try to fix it
- **Structure and routine** can increase the sense of "being on top of things"
- **Consistency** – get the "team" (family, friends etc.) moving in the same direction, with the same expectations
- **Add positives** rather than taking them away
- **Seek assistance** from as many sources as possible

# Suggestions for managing challenging behaviours

The case studies in this section are based on real situations. We offer suggestions for managing behaviours that may be tailored to suit your needs.

The most common challenging behaviours are aggression, socially inappropriate behaviour, inappropriate sexual behaviour and reduced drive and initiation.

## Dealing with aggression

ABI can damage parts of the brain that are responsible for controlling emotions. While anger and frustration are normal emotional responses, when they are expressed as verbal or physical aggression – swearing, shouting, abusive threats, hitting, pushing, assault – they are a problem. A person with ABI can have real difficulty managing their anger.

*Chris was 35 when a car accident left him with a brain injury that caused poor memory, impulsive and rigid thinking, and low frustration tolerance. His ability to process things slowed, so it would take a while to absorb information and to understand instructions. Chris lived with his sister, Lucy, in their family home. Lucy did all the cooking and cleaning, while Chris had little to do during the day. Lucy complained that Chris would shout and swear at her, that he was often selfish and demanding, and that he did nothing around the house.*

*Counselling for Chris was not useful because he could not recall the counselling sessions, and he did not perceive that his aggression was a problem. At times, Chris would become enraged when people misunderstood him or tried to force him to do things he did not want to do. One day, when Lucy was at the end of her tether and ready to leave home, she yelled at Chris, telling him he was “useless” and “would be nowhere” without her. Chris responded by throwing a drinking glass and a sharp knife at his sister.*

**Avoiding triggers:** The main things that triggered Chris's anger were: boredom, being asked to do things he did not want to do, not understanding Lucy's fast speech, and being called "useless". Lucy learned to be more mindful of her reactions toward Chris's behaviour. She made an effort to speak more slowly, to use calm, reassuring tones, and to keep sentences short. She tried not to remind Chris of how much he needed her.

**Avoiding battles:** When Chris began shouting or swearing, Lucy learned to walk away. She avoided raising her voice, name-calling or arguing, as those approaches just made him angrier. If it was something important, she would bring it up later when Chris was not tired or angry.

**Safety:** Rules were put in place to keep people safe. If Chris became physically aggressive, Lucy would leave the room immediately. She would return after about 15 minutes, when he had calmed down. Lucy found this difficult at first but with consistent practice, she felt more in control of the situation. Glasses were replaced with plastic tumblers, and sharp knives were locked away to reduce opportunities for throwing things.

**Recognising the signs:** Lucy learned to recognise when Chris was becoming frustrated. She was able to distract him by changing the topic, which stopped his frustration from escalating to aggression.

**Meaningful activities:** Chris was often bored, which made him irritable and aggressive. He was referred to a case manager, who found him some garden maintenance work, and who established more structure in his week by planning and writing down tasks, step-by-step, that Chris could follow each day.

**Seeking support:** Lucy attended counselling at her community health centre, and a carer service paid for regular respite weekends to give her a break. A council Home Help program also assisted with weekly cleaning.

## Dealing with socially inappropriate behaviour

Socially inappropriate behaviours are those that may be considered annoying, intrusive, disruptive, uncooperative or unlawful. The type of behaviour you consider to be “challenging” depends on what is typical for your social circle, your levels of stress and patience, and the degree of support you have available. Some behaviour may present a risk or danger to self or others. Examples might include:

- Tactless remarks
- Standing too close to strangers
- Actively doing things to seek attention
- Refusing to follow toilet or shower routines
- Crossing roads without watching the traffic
- Lighting fires inappropriately

*Con is a 57 year-old man who suffered a stroke three years ago. As a result, he developed significant memory problems, difficulties with problem-solving, physical slowness, reduced initiation and motivation, and depression. Con's wife, Maria, reported that he would eat the wrong foods, refuse to exercise and refuse to shower.*

*Con felt annoyed at Maria's “fussing” and sometimes didn't shower because he didn't like being reminded so often. He loved all the foods he wasn't supposed to eat and would eat them when she had gone to bed. Maria became so anxious and stressed with his behaviour that she developed high blood pressure. When they took a respite holiday however, the arguments and problems disappeared. They enjoyed the break enormously and felt relaxed, even after returning home.*

**Negotiation:** Con and Maria made an agreement about showering, based on Con's idea of what was practical for his lifestyle. They agreed he would shower three times a week: Mondays, Thursdays and Saturdays. To provide Con with structure, Maria wrote a timetable of showers on his calendar, and agreed to remind him about them only once.

**Adding positives:** Maria reviewed Con's meals with a dietician so that snacks were a regular part of his diet, with sugar-free lollies as treats in between. She also adjusted the weekly shopping to include fewer of the items that were bad for Con's diet. Con's day was also restructured to include a walk with a friend each afternoon.

**Respite:** Respite holidays were increased to four a year to give Con and Maria something to look forward to, and to reduce stress.

**Seeking support:** Maria attended a local carer-support group and scheduled a regular timeslot each week for an activity she wanted to do. She also had counselling to address her anxiety issues.

## Dealing with inappropriate sexual behaviour

After an ABI, changes in the person's ability to control their behaviour, and changes in how they read signals from others, can have a large impact on how their sexual behaviour is viewed.

Some examples of inappropriate sexual behaviour include kissing, hugging and touching other people's breasts, groins or buttocks, when they do not want to be touched.

Sexually inappropriate behaviour does not necessarily mean that the person needs more sex or requires a sex worker. They may want more physical contact with others, but have limited opportunities.

For people who acquire a brain injury before they reach adulthood, the social skills for forming sexual relationships are often not properly developed, which often means they make clumsy sexual manoeuvres.

*Leon is an 18 year-old who contracted encephalitis at age 12, leaving him with poor speech and greatly reduced mobility. Unable to care for him, Leon's family placed him in a group home. Leon would frequently get into trouble for grabbing female workers' breasts, touching their bottoms, lifting their skirts and making sexual comments to them.*

*Leon would go home to his parents' house on weekends, where his difficult behaviours continued. He would leer at his sister's friends, make suggestive comments to them, try to greet them with hugs, or touch their legs. His sister no longer felt comfortable having her friends over. Leon's sexual behaviour didn't seem planned however, it appeared only to happen when the opportunity arose. For example, touching staff inappropriately when they were serving his food, or helping Leon with showers or dressing.*

**Avoiding triggers:** Obvious behaviour triggers were identified and workers learned to avoid leaning directly over Leon when attending to him and avoided turning their backs to him if within arms' reach. A new dress code for staff excluded skirts (to avoid lifting) and tight-fitting tops (to minimize targets).

**Introducing consequences:** Some consequences were introduced for Leon's behaviour. Workers were trained to take a no-nonsense approach to any sexual behaviours. They would immediately tell Leon if his behaviour was inappropriate and suggest a better way to express a point he wished to make, or they would leave him alone for a brief period before restarting their tasks.

**Alternative activities:** Other means of non-sexual, physical contact were explored, such as shaking hands and massage, and other means of sexual gratification were trialled, including access to a professional sex worker and to sexually explicit videos and magazines.

**Learning new skills:** Leon gained benefit from a social skills program at the local neighbourhood house. He practised keeping appropriate physical distance from others, talking to others without touching them and learning which comments were not acceptable.

**Extended support:** At home, Leon's sister and one of her friends helped Leon to practise by talking with him about things other than sex. They enforced a strict rule of "no sex talk", and would withdraw attention for a brief time by turning or walking away if he broke the rules.

**Adding positives:** Leon's father began to take him bowling on Saturdays, giving his sister time to relax with friends at home. The outing was fun for Leon too, and boosted his self esteem.

## Dealing with reduced drive and initiation

Injury to the brain can cause adynamia, a condition in which people experience a lack of drive and difficulty initiating activity. A person with adynamia has trouble getting things started or doing things for themselves. They often appear disinterested, lethargic or uncooperative.

For example, they may not wash, eat or groom themselves without prompting from others. They may sit on the couch all day, not start conversations, or need constant encouragement to do tasks. It often helps to provide cues, structure and to develop a routine.

*At 46, Anna experienced a heart attack that deprived her brain of oxygen for some time (a hypoxic brain injury). After months of rehabilitation, Anna returned home to live with her husband, Sam, and their two children. Since then, the family has had difficulty coping. They can't get Anna to do anything. She lacks spontaneity and no longer contributes ideas to conversations. She doesn't answer the phone if it rings, or even ask for a drink if she is thirsty. Sometimes Anna lies in bed all day, or she sits watching the television for hours on end. While she is physically capable of doing most tasks, she often loses track of what she is doing. For instance, she starts to go through the steps of showering, but sometimes ends up back in bed before completing the routine.*

*Anna's family is very distressed over all these changes. Sam sometimes feels like Anna is being difficult on purpose and not trying hard enough. The children are really struggling to come to terms with their 'new' Mum, and are starting to withdraw from meaningful contact with her.*

**Keeping informed:** Anna's family received some education and written information about adynamic behaviour and hypoxic brain injury, which gave them a better understanding of her situation and how to assist her.

**Counselling:** Time spent in family counselling gave Sam and the children some coping strategies, and addressed their grief and loss issues in relation to Anna's condition and all their changed roles.

**Enlisting support:** Skilled attendant-care workers were engaged to assist Anna in developing routines and to maximise her independence, reducing some of the burden of care on her family.

**Improving structure:** A large, visible timetable was introduced to give some structure to Anna’s weekly activities.

Mon	Tue	Wed	Thur	Fri
9am wake	9am wake	9am wake	9am wake	9am wake
10am shower	10am shower	10am shower	10am shower	10am shower
2-4pm Shopping Time with Sam	2-4pm Worker: Di Make cake Collect kids	2-4pm Worker: Di Shopping Cook dinner	2-4pm Worker: Amy Gardening Collect kids	2-4pm Worker: Amy Shopping Gardening

**Meaningful activities:** In order to engage Anna, activities had to be relevant, meaningful to her, and easily achievable, such as cooking or watering the garden.

**Motivation through encouragement:** The family learned that Anna was more likely to follow through on tasks when praise and encouragement for her behaviour were forthcoming.

**Consistency:** It was important that Sam, the children and workers were patient, persistent and consistent in maintaining routines. It took a long time, but Anna was able to learn to use visual cues and to start doing more things herself, with less prompting from others.

## Conclusion

Even for experts, managing challenging behaviour is not easy, so it is not surprising that families can find these issues particularly difficult. Still, it is important to remember that change and improvement can occur.

Some families will find that behavioural issues are significantly improved with outside assistance. Others will find that with strategies in place, behavioural issues still occur, but less often or with less intensity.

Behaviour management is often about finding creative ways to manage the situation you find yourself in, and not necessarily trying to “fix it”. Everyone’s situation is different, and it may take time and some trial and error to find the right solution. Don’t be afraid to try new approaches, even if they seem strange at first, and to seek help at any time - there are many sources of information and support available.

Finally, it is important to remember that it is usually easier to change or manage the environment and to develop coping strategies for family members, than it is to persist with trying to change the person with ABI.

## For more information

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