

Changes in Thinking and Behaviour

THIS FACT SHEET describes the types of changes that can occur in thinking and behaviour due to acquired brain injury (ABI) and suggests some strategies to help manage or compensate for those changes.

After a diagnosis of acquired brain injury (ABI), changes often occur in a person's thinking and behaviour that can be very challenging to live with for the person concerned and their carers and family.

It's sometimes more difficult to adjust to these changes than the physical ones because they are harder to perceive and to associate with a condition. For example, irritability and sitting around the house all day could become common behaviours for someone with ABI. Someone with multiple sclerosis might cry easily and often be exhausted.

A brain injury can alter a person's personality quite dramatically too.

Friends, relatives, employers, even a spouse, may not understand or readily accept these sorts of changes. But there are plenty of management and coping strategies to help your situation. A neuropsychologist can make an assessment of changes that have occurred and devise a plan for both the person and their carer.

In general, the best approach is to help the person help themselves; to do things independently.

Attention and Concentration

When it is difficult to pay attention and concentrate on one thing, it's hard to take in information and to learn, such as working out how to use a new mobile phone. Be realistic about a person's abilities to learn new skills and routines. These strategies may help them to focus.

- > Repetition helps, going over the same thing again and again.

- > Minimise distracting background noise, such as radio, TV, or people talking nearby.
- > Tackle new or difficult things when the person is fresh. Stress and fatigue make concentration more difficult.
- > Say things as often as necessary and think of ways to help the person remember. For example, to help remember people's names, try associating a new person's name with a physical feature – "Carole with the curls".
- > Try to avoid saying – "I've just told you that" – it's very disheartening.
- > Say things simply, one at a time – "Do you want porridge?" wait for the answer then, "Do you want a cup of tea?".

Memory

If short-term memory is a problem, the person may not be able to remember a string of requests, follow directions or remember how to pay a bill on the internet, but their old memories remain intact. Consider these strategies.

- > Use a large calendar that shows the day and date.
- > Keep a daily routine. If you break the routine (e.g. going to visit friends), give the person a written list or timetable to refer to so they feel more in control.
- > Help the person to use a daily planner to write down jobs and routines, keep it in the same place. Encourage its regular use.
- > Help to jot down names of new acquaintances, old friends, and details of important conversations to remember.
- > Talk about things from the past that the person does remember.

- > For people with severe memory problems, use labels on rooms, drawers, shelves and objects.
- > Use existing skills and abilities and try to find activities that don't require much learning.
- > Minimise stress and fatigue – these can hamper memory.

Planning, Organisation and Problem-Solving

If the brain loses its capacity to plan, organise or solve problems effectively, a person may have difficulty making decisions, organising their time and working out how to do things like cooking a meal. They may also have trouble knowing when, where and how to ask for help.

Some people cope with familiar tasks but need help with new or complex ones. Others need help organising the simplest tasks, such as changing clothes. Some people become unable to see the consequences of their actions and find it difficult to learn from their mistakes. Others have trouble applying their knowledge in different circumstances – they learn to manage the toilet at the rehabilitation centre, but not at home. Keep the following suggestions in mind:

- > Use a daily planner and stick to a routine.
- > Help write down things that need to be done over days/weeks and use a diary for important events.
- > Encourage the person to do one thing at a time.
- > Break tasks into small steps to be completed every time. Rehearse the steps, talking through them, one by one. Then remind them gently of each step as they come to it – “Fill the kettle, now plug it in. Switch it on, right. Get the tea cups ...”
- > Keep things needed for everyday tasks in the same place.
- > Encourage the person to do things independently. Don't complete tasks for them.
- > Minimise distractions and let them do things in their own time.

Spatial Difficulties

A person's understanding of how things relate to each other in space may be affected. For instance, they may have difficulties moving through a doorway, putting on a shirt, setting the table or finding their way to the bathroom. Once they can understand the problem, some people compensate well, others will always need their carers to help them. Visual perception difficulties have a similar impact and are discussed in Fact Sheet 12: Vision Problems.

It may help to:

- > Talk through activities as you do them – “Come into the hall, walk straight ahead...” – arrows on the floor can also help at home.
- > Draw attention to objects or activities on the affected (non-seeing) side.
- > When moving about, encourage the person to set orientation landmarks that are meaningful to them.

Insight and Awareness

Brain injury or an illness that affects the brain, like dementia, can leave some people with little understanding and awareness of their disabilities. This can lead to someone attempting things beyond their capabilities, for example or being less able to monitor their behaviour or understand its effect on others (e.g. speaking too loudly).

A person may find it difficult to understand social niceties and other people's feelings. Others may not pick up on the usual indicators that you are tired or unhappy. A person's personality can change in a variety of ways too, becoming more self-absorbed perhaps, or withdrawn.

- > As difficult as it can be, try to be reassuring toward the person. These changes are the result of their condition and are often very disturbing for them too.
- > Allow the person to make decisions (as much as possible).
- > Be clear about their ability to take risks. Set clear limits and communicate these to them in a simple, straightforward manner.
- > If the person's behaviour is annoying, try to distract them with something else to do.

Use positive statements like “Try this”, instead of “Stop that”.

- > Explain the effect their behaviour has on others by using clear, straightforward words. Dropping hints won't work.
- > Accept their comments – arguing only makes matters worse.
- > If the person is confused easily, maintain a quiet, familiar environment and limit visitors.

Loss of Control or Disinhibition

When people experience loss of control or disinhibition in their behaviour, it can be disturbing and taxing on carers and families. It's hard when a loved one's condition causes them to become an incessant talker or to have aggressive outbursts regularly. Perhaps they are restless, fidgeting and pacing or wandering off and getting lost. They may be impulsive in new ways from spending money to overeating. Disinhibition can also lead to making persistent sexual demands on a partner or inappropriate sexual remarks. Try these tips when managing behaviour:

- > Become aware of situations and triggers that can provoke unacceptable behaviour and avoid them.
- > When awkward moments occur, it's best not to react. Simply say “this is not the place for that” and move on to another topic. Ask others to do the same.
- > Occasionally, actions may cause emotional hurt or distress. Encourage people not to take it personally.
- > Remember, arguing only makes matters worse.
- > Create a safe environment so that outbursts won't result in injuries – remove yourself from the situation if necessary.
- > If possible, allow the outburst to pass, but don't ignore or trivialise behaviour that might harm others – take steps to defuse it.
- > When addressing the person's behaviour, be assertive and confident. Use clear “I” statements and provide an alternative:

- > “I don't want you to do that, I want you to do this...”
- > Always reassure the person that you understand their response is part of their condition.
- > Respond in a positive manner to behaviour that is appropriate and acceptable.
- > Try to highlight what the person can do, rather than what they cannot do.

Loss of Motivation or Drive

Brain injury sometimes causes people to experience a loss of motivation, drive and the ability to get things started. This person may seem lethargic, disinterested or uncooperative. They may not wash or eat without prompting. They may fail to initiate conversations or they may sit on the couch all day. It often helps to provide cues, structure and direction.

- > Establish tasks and activities as part of a familiar routine, and provide checklists for tasks.
- > Involve them in everything that is happening, encourage them to contribute and give praise often.
- > Encourage them to do easy things that provide some stimulation – music, TV, reading, talking, crafts.
- > Find activities that are relevant and meaningful to them. Join in or ask others to participate sometimes.
- > Remember, it is okay to do nothing at times.

Other Common Effects

Fatigue and depression are both very common effects of brain injury that can make other symptoms appear worse. Fatigue is discussed in more detail in Fact Sheet II: Managing Fatigue.

Depression can be caused by a person's condition or their psychological reaction to it. Counselling, therapy (e.g. Cognitive Behaviour Therapy) or medication can make a huge difference to a person's mental well being. It's important to see your doctor if you suspect depression is an issue.

Sometimes changes in mood are part of a grief response or the frustrations of dealing with the situation. These are discussed in Fact Sheet 18: Grief and Loss and Fact Sheet 19: Coping with Stress.

Speech and communication difficulties, such as difficulty expressing thoughts, finding words and reading body language, are discussed in Fact Sheet 7: Speech and Communication Problems.

Seeking Support

There is no need to bear hurtful or inappropriate behaviour beyond reasonable limits.

Neuropsychologists can assess these changes and help develop behaviour management programs. Some people benefit from having a neuropsychological assessment done every few years. Occupational therapists can also help with management strategies at home or work. Speech therapists can help with communication strategies.

Respite: Carers and family members, do consider using respite care for regular breaks to ensure your own well being. Your health is important too! (See Fact Sheet 15: Respite and Residential Care).

Contacts

Try your local doctor or your condition-specific support agency (See Contacts pg 7) who can help you to decide which specialists might assist with your situation.

Specialists such as neuropsychologists, occupational therapists or speech pathologists are usually found through large hospitals or rehabilitation centres. Ask at your regular treatment centre for referrals. Or try the ABI Behaviour Consultancy, telephone: (03) 9383 7176.