

Insight and awareness after brain injury



This publication is part of Headway's *Effects of brain injury* series. To browse through our publications on a range of issues relating to brain injury and download these free-of-charge, visit www.headway.org.uk/information-library.

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Introduction

Brain injury can result in a range of physical, emotional and behavioural, psychological and cognitive changes. However, sometimes a brain injury survivor may be unaware that these changes have taken place, and they may deny them even if they are pointed out - this is referred to as 'lack of insight'.

This publication is intended for the family, friends and carers of a brain injury survivor who lacks insight. It provides information about what lack of insight is, strategies for managing lack of insight, support services that can help and information regarding the legal frameworks that protect people who lack insight.

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The information in this publication does not replace clinical guidance from medical professionals. You should always seek advice from a GP or other suitably qualified professional for help with managing the effects of brain injury.

How can insight be affected after brain injury?

Insight, also referred to as self-awareness, is the ability of a person to observe and reflect on their own thoughts and actions. Brain injuries, especially injuries to the frontal lobes, often cause this ability to be significantly affected. This can be a particular problem for both brain injury survivors and their family, friends and carers. It can be distressing for survivors, because they may struggle to understand why people are restricting them from doing certain things. Families, friends and carers can find it problematic and upsetting because the brain injury survivor may behave inappropriately without being aware that there is anything wrong with their actions.

Issues with insight can also have an impact upon rehabilitation. Those affected by a brain injury may show a lack of understanding about how their cognitive problems impact upon things such as relationships with family and friends, activities of daily living, driving and general life in the community. They may therefore struggle to realise why rehabilitation is necessary, and refuse to engage in rehabilitation services. Other aspects of life that can be affected by a lack of insight are legal matters, safety and employment.

It is very common for people to have insight for some things but not for others. For example, a person may be aware of their physical injuries but unaware that they have a memory problem; or they may be able to demonstrate relatively good memory but be totally unaware of other problems.

There are dangers in assuming a lack of insight for all decisions, as a person with brain injury may not be allowed to develop responsibility for their actions. Insight commonly changes over time as well; for instance, some people may display reduced insight in the early days of their brain injury, but come to regain insight later on as they recover from their injury.

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Strategies for supporting survivors with insight issues

Identify the underlying cause of insight issues

There are a number of reasons that a person may have a lack of insight. It is important to identify these, as this may determine how you intervene or approach the problem. Below is a list of problems that a person may experience following a brain injury that can lead to a lack of insight:

- Inability to monitor own behaviour (self monitoring)
- Impaired reasoning and thinking skills
- Impaired memory Inability to concentrate or retain attention
- Emotional difficulties or problems with accepting the disability

Some strategies for dealing with these problems are as follows:

- If the problem is with **self monitoring**, strategies that raise awareness of performance may be helpful, such as checklists and providing feedback in the form of videos or discussions - for more information on this, see section *Provide feedback and information*.
- If the problem is related to **reasoning or thinking skills**, concrete goal setting, planning and helping with decision making may be the approach to take. For more information on this, see our publication [*Decision making difficulties after brain injury*](#).
- If the main issue is **memory**, then memory aids and strategies may help. For more information on this, see our publication [*Memory problems after brain injury*](#).
- Issues with **concentrating or retaining attention** come under the term 'executive dysfunction'. For more information on this, see our publication [*Executive dysfunction after brain injury*](#).

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- If the issue is **emotional coping or acceptance of the disability**, counselling and support groups may be helpful - for more information on this, see our publication [*Psychological effects of brain injury*](#).

Some people with severe injuries may have problems at all of these levels and require more than one approach to improve awareness.

Link activities to goals

- Try to relate activities and tasks to the person's own goals and plans, to attempt to increase motivation and participation. For example, *"we are working on these memory strategies so that you are able to live on your own."*
- Having reduced insight might make people unrealistic and unachievable goals for themselves as they may not understand their own limitations. Assist the person to set realistic goals and plans, so that they are more manageable and achievable. For instance, encourage the person to break down large goals into smaller ones, and celebrate successes, no matter how small.

Avoid arguments and confrontation

- Try to avoid directly confronting or challenging the brain injury survivor's ideas about their capacity - this can lead to conflict, disagreements and anger. If the person insists on there being no change in their behaviour, allow the conversation to drop for the time being. Later, when the person is calmer, give general information about brain injury and the kind of difficulties that can be experienced. This can shift the focus from being a personal problem to something more general. For example, *"people with a brain injury sometimes have trouble with their anger or temper. Do you think you might have any problems like that?"*
- If you are struggling with managing the brain injury survivor's anger over their lack of insight, refer to our publication [*Anger after brain injury*](#). You can get

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further information and support by contacting the Headway helpline or your local Headway support group or branch.

Encourage open communication

- Try to encourage the brain injury survivor to talk to you about how they are feeling. Giving them time and the opportunity to reflect on their own experiences might make it easier for them to identify and accept any changes themselves rather than being told about them.
- Do not try to confront the brain injury survivor about their lack of insight if they are feeling tired, upset or angry. It will be easier to discuss things when they are in a calmer frame of mind and able to engage in a discussion.
- Use clear and direct, but gentle language when explaining to the brain injury survivor in what way they are lacking insight. Try to use specific examples and highlight any consequences that this might have. For example, *“because your reaction times are very slow, this means that you are not able to drive at the moment.”*

Provide feedback and information

- Providing frequent, non-critical feedback about performance or behaviour can be one way to improve insight and awareness.
- When directing the brain injury survivor’s attention to specific areas of difficulty, it is important not to dwell on the problem so much that they become distressed. Direct attention to any improvements, strengths or changes made; this is equally as important so that the survivor does not become de-motivated.
- Involve the brain injury survivor in rating their own performance in different areas, particularly focusing on areas they would like to change.

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- Provide opportunities for the brain injury survivor to get feedback from other people, such as friends and other family members. It is important that they too understand the effects of brain injury on the person's ability to carry out certain tasks and how their feedback can help. Consistent messages are a vital part of ongoing rehabilitation.
- Do not be distressed if the brain injury survivor does not acknowledge the change in behaviour even if you show them evidence, such as a recording of themselves. Even with such evidence, some people who lack insight may struggle to understand that their behaviour is changed, and they may try to justify the new behaviour, for example by saying that they have always behaved that way.

Seek support

Supporting a person with reduced insight is one of the most difficult tasks for relatives and carers after brain injury. As well as taking on the responsibility for solving problems that reduced insight causes, carers and relatives have a strong emotional involvement with a brain injured person, which can make doing the right thing even more difficult.

- The most important thing in this case is to obtain support from an outside source; preferably someone who is not directly involved, but who has experience of the effects of brain injury. Carer support groups are often effective for this purpose. Getting support from the outside helps provide an independent view of the person's lack of insight and can help to develop effective strategies to deal with problems. It can also prevent the feelings of isolation that carers or relatives may feel.

You can contact your local Headway group or branch for details of their carer support services. Alternatively, the Headway helpline can help with locating carer support services that are local to you. More information about support available for carers is available in our publication [*Caring for someone with a brain injury*](#).

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- You may also feel that it is necessary to seek professional support for the brain injury survivor. If this is the case then you should speak with your GP about getting a referral to a neuropsychologist. These are professionals that support brain injury survivors with the psychological and emotional effects of brain injury, so they will have an understanding about the challenges that having a lack of insight can bring.

Be risk aware

Be sensitive to any risks or dangers that the brain injury survivor may place themselves or others in as a result of their lack of insight. For instance, if they do not recognise that they have a memory problem, be mindful of issues such as leaving a cooker unattended or forgetting to lock doors before they leave the house. Or if they do not recognise that their driving skills are affected, make them aware of the legalities of driving after brain injury (for more information on this topic, see our publication [Driving after brain injury](#)).

Educate others

If appropriate, explain the issue of lack of insight to other key people in the brain injury survivor's life, such as close friends. This will help them to accommodate for any changed behaviour that the person displays. You might find it useful to share this publication with them.

Legal frameworks that protect people who lack insight

There are two main pieces of legislation that exist to help or protect people with reduced insight who are at risk in some way: The Mental Capacity Act (2005) and The Mental Health Act (2007). These are discussed in further detail below:

The Mental Capacity Act (2005) provides a framework to make decisions on behalf of people who are clearly not able to make decisions for themselves. This particularly applies to decisions about where to live and financial decisions. People who lack insight may not have the capacity to make these decisions; therefore this act sets down how capacity is assessed, who can make decisions

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on behalf of a brain injured person who lacks capacity, and how their ‘best interests’ can be decided. Some important aspects of the Mental Capacity Act are:

- Capacity is assumed to exist until shown otherwise
- Capacity has to be assessed for each different situation or problem separately
- All reasonable steps must be taken to establish capacity (this is especially important in people who have communication difficulties following brain injury)
- If a person has made any statements about their wishes in advance, these must be taken into account

If a person lacks the capacity to make a specific decision, all those involved in their care should also be involved in establishing their ‘best interest’. Independent Mental Capacity Advocates (IMCAs) can offer independent advocacy on behalf of a brain injured person who is incapacitated, especially if the issue is around where to live or how to spend money.

For further information on the Mental Capacity Act and the role of IMCAs, see our publication [Mental capacity: supporting decision making after brain injury](#), or visit the Office of the Public Guardian website at www.publicguardian.gov.uk.

The Mental Health Act (2007) stipulates how a person with brain injury can be detained against their wishes if their behaviour leads to significant risks to themselves or others. In this case, the person has to be shown to have some kind of mental disorder (this includes the types of behavioural changes that occur as a result of brain injury), for it to be severe enough to warrant detention for an assessment and for it to be in “the interests of the person’s health, safety or the protection of others”. It also has to be shown that the person would not willingly accept treatment. The reason for this is commonly that the brain injured person does not see that there is a problem.

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People who are detained under the Mental Health Act have a right of appeal against their detention, which is heard by a judge in the presence of an independent panel (usually a doctor from outside the service and a layperson).

Specialist legal advice should always be sought on these matters and the Headway Head Injury Solicitor's Directory provides a list of approved firms with experience of dealing with brain injury issues. The directory can be accessed from the Headway website at www.headway.org.uk/supporting-you/in-your-area/head-injury-solicitors-directory or by calling the Headway helpline.

For more information on the Mental Health Act, visit the Department of Health website at www.dh.gov.uk. Mind, the mental health charity, also has some excellent information on the subject on their website at www.mind.org.uk.

This publication received a Highly Commended Award at the British Medical Association Patient Information Awards 2017.

As a charity, we rely on donations from people like you to continue being able to provide free information to those affected by brain injury. To donate, or find out how else you can get involved with supporting our work, visit www.headway.org.uk/get-involved.

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