

## Strategies for: coping with lack of insight

This 'Strategies for Coping' factsheet gives an overview of some of the difficulties you might face coping with lack of insight following a brain injury. We are all different, and how you may feel won't be the same as other people, even if they have similar injuries to you.

### Introduction

Your brain injury can result in a range of physical, emotional and behavioural, psychological and cognitive changes. However, you may not be aware that these changes have taken place, and have difficulty in coming to term with this, even when this is pointed out to you. We call this 'lack of insight'.

This factsheet is intended for you, your family, friends and carers. 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.

We have divided our factsheet into three sections:

- Section 1 outlines in more detail what 'lack of insight' is, and how you might be affected.
- Section 2 is aimed at your family, friends and carers, and deals with techniques and strategies which can help them to cope when you have difficulties with lack of insight. It is a good idea for you to read through section 2 so that you can begin to understand what those around you are trying to do to help you the best they can.
- Section 3 looks at the legal frameworks that exist to protect people who lack insight.









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# **Section 1: What is lack of insight?**

Insight, also referred to as self-awareness, is your ability of to observe and reflect on your own thoughts and actions. Your brain injury, especially if there is damage to the frontal lobes, may cause this ability to be significantly affected. This can be a particular problem for you, your family, friends and carers. You may find it distressing as you may not be aware why people around you may be stopping you from doing things you once took for granted.

Your family, friends and carers can also find it upsetting as you may have said or done things without knowing what you have done may be wrong. It is possible that lack of insight can also slow down your rehabilitation. Many people in your situation often struggle to recognise that you need help with your rehabilitation and often refuse to take part even when help is offered.

You may not be completely aware of how your actions impact on relationships with your family and friends, and how your normal daily life may have changed. Every day, we all think about lots of things that affect the way we speak, or the way we act. You, for example, may think about money, your job, or even, 'should I cross that busy road'? Sometimes you may believe that what you have done or said is completely rational, however those around you may question what you have done.

One of the most frustrating things is that you may have clear insight for some things and not others. For example, you may be aware that you have physical injuries, and completely unaware that that you are having difficulties remembering things. On the other hand, (and you can see why it is so frustrating), you may have good recall and memory and be totally unaware of other problems.

The most difficult problem for those around you, is they may assume you lack insight for all decisions, and could mean you are not allowed to develop and take responsibility for your actions.

Insight, and your ability to understand the consequences of your actions changes over time; for instance, you may display reduced insight in the early days of your recovery, but find yourself improving as time passes. Coming to terms that you may lack insight is one of the most important steps in your recovery. This is one of those situations where you will almost certainly need a lot of help and support

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from you family, friends and carers. Your family and friends may never have been asked to give support to someone who has had a serious brain injury, if this is the case they may get things wrong occasionally. Try and remember that they will be doing their best to make you feel better and sometimes they will have the same frustrations as you, particularly if things don't always work first time.

# Section 2: Help and advice for families and carers

This section is to help those family, friends and carers who have regular contact with somebody, who, following a brain injury, may be struggling with lack of insight.

### Identify the cause

There are many reasons why a person may lack of insight. It is important to identify these because this will determine how you intervene or approach any issues regarding lack of insight. Listed below are some of the problems someone may experience following a brain injury that can lead to lack of insight, together with brief strategies to start planning help:

- Self-monitoring Strategies that raise awareness of performance may be helpful, such as checklists, or providing feedback in the form of videos and discussions.
- Reasoning or thinking skills Concrete goal setting, planning and helping to make decisions is a good place to start.
- Impaired Memory More detailed help is given in Headway Nottingham's 'Coping with memory problems'.
- Inability to concentrate or maintain attention The medical term is 'executive dysfunction'. More detailed help is given in Headway Nottingham's 'Coping with executive dysfunction'.
- Emotional coping or acceptance of the disability Counselling and support groups may be helpful There are no 'quick fixes', and somebody you care for may have problems at all of these levels and require more than one approach to improve awareness. In addition to the ones shown above, Headway Nottingham have produced a number of other information factsheets, they may help you, your family and friends understand some of these issues.











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# Tips for families and carers

#### Link activities to goals

Lack of insight in people with brain injuries may mean that they may set themselves unrealistic and unachievable goals because they may not fully understand their own limitations. The best tip here is set realistic goals and plans that are manageable and achievable. For instance, help break down large goals into smaller ones, and make sure than each is completed in turn. Celebrate success, no matter how small.

#### **Avoid arguments and confrontation**

This is of course easier said than done. Try to make a conscious effort to be calm and speak gently, even if you think the argument wrong. It is best to avoid direct confrontation if you think lack of insight is part of the problem as this can lead to conflict, disagreement and anger. Try to gently direct the conversation away from what may be causing tension and stress. It won't always work, but talking about something more pleasant may help to calm things down. When things are calmer, start to discuss the issue more general terms. Generally, it is better for everybody to avoid arguments when they are tired, upset or angry.

#### **Encourage open communication**

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It is always better when somebody feels able to discuss, and be open about a problem, rather that always being told there is an issue. As a friend or carer, listen to what is being said; this is especially important when anybody uses their own experiences to relate how things affect them. In this situation they are usually the first to accept anything that will make things easier in the future. Try to reply in clear, direct, but gentle language, to explain how lack of insight may be affecting their actions. When explaining to somebody in what way they may be lacking insight, specific examples may bring a better understanding, for instance, 'driving is not a good idea for a while because you don't seem to be reacting too quickly at the moment'. As time passes you will find yourself getting better at listening to problems and replying with good advice.













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#### Provide feedback and information

Occasional, non-critical feedback about performance or behaviour helps all of us and is particularly important for someone suffering from lack of insight due to brain injury. A few general tips are listed below:

- Don't dwell on any specific problem, nobody likes being lectured.
- On the other hand, everybody likes to know when things improve, it increases our motivation and makes us feel better.
- We can be our own best, and sometimes worst critic. Most people like to assess themselves when they have done something important as it helps us identify how we can make things better in future.
- Encourage feedback and help from other people, providing they are aware of the problems and how their feedback can help.
- Consistent messages are a vital part of ongoing rehabilitation. This means that whatever help and answers you give need to be thought out to make sure things remain level.

Sometimes, when somebody has suffered a serious brain injury, it is difficult for them to acknowledge there may be changes in their behaviour, particularly if they are struggling with lack of insight. Even, when confronted with evidence such as an audio or video recording, some people still can't accept that things have changed. A common reaction is, 'I've always done that'. This can be distressing for everybody around who may themselves be under pressure. Now may be the time to seek professional support.

#### **Professional support**

Supporting a person with reduced insight is one of the most difficult tasks for relatives and carers following brain injury. As well as taking on the responsibility for solving problems that loss of 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. 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 help prevent feelings of isolation that carers or relatives may feel. There are many











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professionals who can offer support and reassurance to help you cope It is best to seek support from professionals who specialise in brain injuries, such as Clinical Neuropsychologists or Clinical Psychologists. These professionals are expert in the assessment and intervention of behavioural, emotional and cognitive problems caused by brain injury.

You can access these professionals through a GP referral or privately. Headway Nottingham could also help with finding details of private therapists in your area. In some instances, you may be able to refer yourself to a local self-help group if there is one in your area.

#### Risk awareness

When someone struggles with lack of insight, they may not be aware of risks they may put themselves in. For example, problems with memory may mean they forget to turn off the cooker or lock the doors when they leave the house. Driving can be a particular problem if they are not aware their skills may be impaired, or of the legal issues of driving following a brain injury.

It is of course impossible for anybody to recognise every risk or danger; however, time and patience will make it easier to identify where things may go wrong.

#### **Educate others**

Not everybody will be aware there may be issues that lack of insight may bring to someone who has suffered a serious brain injury. Where appropriate, try and explain to those around, (family, friends and other carers), about some of the difficulties. This will help them to accommodate for any changes in behaviour and help to make everybody's life a little easier. You might find it useful to share this factsheet with them.











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#### Section 3: 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 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 must 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 considered.

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.

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 must 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 must 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 Head Injury Solicitor's Directory produced by Headway UK provides a list of approved firms with experience of dealing with brain injury issues. The directory can be accessed from the Headway UK website at <a href="https://www.headway.org.uk/supporting-you/in-your\_area/head-injury-solicitors-directory">https://www.headway.org.uk/supporting-you/in-your\_area/head-injury-solicitors-directory</a> or by calling the Headway UK national helpline, on 0808 800 22 44.

For more information on the Mental Health Act, visit the Department of Health website at <a href="www.dh.gov.uk">www.dh.gov.uk</a>. Mind, the mental health charity, also has some excellent information on the subject on their website at <a href="www.mind.org.uk">www.mind.org.uk</a>. For more information on mental health and brain injury, refer to the Headway UK factsheet <a href="Mental health and brain injury">Mental health and brain injury</a>.

### **Conclusion**

Lack of insight is very common after brain injury. It can take many forms and manifest itself in many different situations. Dealing with these changes requires flexibility on the part of carers and, while the strategies outlined above can be helpful, lack of insight can be one of the most difficult and frustrating problems to cope with. One of the most effective ways of coping with the problem is to seek the support of others with similar experiences.

We hope that this information has helped you to learn that your life after your brain injury will be different. Headway Nottingham are there to help, reassure and support you through these challenges. To help you overcome some of the other difficulties you may be facing after your brain injury, Headway Nottingham have produced a series of factsheets that you can access online.







