

This information booklet is written for people with brain injuries, their families, carers and friends. We hope it will support understanding of brain injury as well as offer ideas to help manage difficult areas day to day.

Difficulties with decision-making after brain injury

This factsheet gives an overview of some of the difficulties you might face when trying to make decisions or choices 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. There are some practical tips to help to make it easier for you to make those important decisions.

Introduction

Every day, all us make decisions and choices that affect how we get through our lives. Minor choices like which toothpaste do I use? or what shall I have for dinner? are usually made without a lot of fuss. More complex decisions regarding relationships, jobs or holidays often take a bit longer. Each of us is different and how we come to these decisions depends on our different cognitive abilities and functions coming together. Some of these can be:

- Long term memory for example, what did I do in the past? and how will it be if I choose to do something?
- Emotion quite important in situations when you make decisions about your family.
- Mood for example, what do I fancy for lunch?

Most of us don't have too much trouble deciding what we want to do, and even when we have think hard about things, we usually get to the right choice.

When people like you have a serious brain injury, the processes involved in coming to decisions or making choices may become muddled. The outcome is that you might find it hard to make the simplest choices, or sometimes struggle to come to any decision at all. At the other end of the scale you might find that you make hasty or impulsive decisions, and this could seem to those around you that you have not thought things through.









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We understand that if you make poor decisions, it can upset you, your family and friends. This can be more serious if for example, money, your business or close relationships are affected.

We will try and help you come to terms with the difficulties you may be having with making decisions and understand why you may be affected, and help you work out how you begin to cope with making decisions.

Decision making and following through with plans

You might find yourself in a situation where you feel that you have made a clear decision and you have come up with a plan of action how you will get things done. In practice your brain injury and the way things now work, may mean you struggle to get to your goal. There may be many problems that might hold you back, and we will try to explain things in more detail.

Forgetting: plain and simple, we all forget things sometimes, but you may find things go out of your mind more than they did in the past. It can be as simple as being distracted by something else, or not remembering what you were doing in the first place. Here are a few examples of the sort of things that you may forget:

- Take your medication.
- Go to an appointment.
- Give your friend a message.
- Everyday jobs, for example, putting the bins out
- Forget to watch your favourite TV programme.

Professional medical people often call this 'prospective memory' and it is the sort of thing that needs you to be alert about your plans throughout the day. Psychologists use the concept of a 'mental blackboard' to describe how we keep things we intend to do in mind (as if written on a mental blackboard). However, you might find that after your brain injury things are easily rubbed off your











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mental blackboard and temporarily forgotten. It might be that you will remember what you were going to do if someone gives you a reminder or gentle nudge.

Self-awareness (Insight)

The cognitive problems you now face that cause difficulties with your decision making or 'prospective remembering' may mean that you don't know or are not aware that you have any problems. You, your family and friends might find this difficult to deal with and may occasionally cause conflict. Most of us have faced criticism from people when they feel we have made a poor decision, or we simply haven't managed to finish a job we were supposed to be doing. One of the first challenges you will have to face if you find yourself in this situation, is to come to terms with the fact that there is an issue, and begin to understand that you may be facing real problems.

This is where your family, friends and professional people around can help. They can encourage you with sensitive feedback and to explain things, and start to make you feel that you really want to learn ways that can help you control the way you make decisions.

Rehabilitation

To work out how you can improve your ability to make decisions, to become better at solving problems and remembering to see your plans through is not a job for you to do on your own. Help from professional people such as occupational therapists or clinical psychologists will help you on the way to rehabilitation. You will find that there are no 'quick fixes' so extra support and encouragement from your family and friends will always help you feel better as you start to re-gain control.

One of the first steps you may take is learning how to manage being impulsive and begin to develop the habit of 'taking a step back', and thinking, even for a moment, about what you are doing. The idea behind this is that you will become better at 'self talk' – this is listening to yourself, and be better able to regulate your decisions, choices and actions.





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Practical help

Goal management training (or help) is one way for you to learn to be better at being clear what it is you are trying to achieve. It can help you work out and keep in mind the steps needed to achieve you goal and regularly check your mental blackboard to make sure you keep important tasks in mind. One study carried out by researchers in Cambridge and Glasgow showed that goal management training, combined with SMS text message reminders to check the mental blackboard, helped people like you with brain injuries to remember to carry out a task. In this case it was to make a phone call to a voicemail service that had to be done four times a day at specific times. This is just an example of a practical exercise that worked for some people. Like everything we attempt that is new, there has to some fine tuning to make sure that whatever help you need is right and effective for you.

The steps below are put in order of the normal way we go about making decisions and choices. We don't always think about it in normal circumstances, but if you feel that you are having difficulty making up your mind, it might help you to read through the list to remind you of what it is you are trying to do.

- GOAL: What is the goal? What are you trying to achieve? What do you want to have happen? What will it look like when you're done?
- OBSTACLE: What is standing or could stand in the way of you achieving the goal? What is the problem?
- PLAN: What is the plan? What do you need to do? Can you write out a checklist? Do you need help to list the steps? Do you need help for any one of the steps? Do you want to do it as a team? Do you think that plan will work?
- PREDICTION: How well do you think you will do? How many can you get done? On a scale of 1 to 10, how well will you do?
- DO: Carry out the plan, perhaps solving problems along the way or revising the plan.
- REVIEW: How did it work out? What worked? Anything that didn't work? Why or why not? What are you going to try next time?







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You can change anything if you think it would be better for you. For example, changing the words to language that suits you. It doesn't matter so long as you feel comfortable and it helps you to make the right decision and finish the job you started.

Practical aids

Practical aids such as diaries, notebooks, wall charts and calendars are invaluable to help you or remind you to do something. Electronic watches, mobile phones, pagers and tablet computers can all be set to give you reminders and cues to do specific tasks, or to check a daily planner. It might not always be easy for you to use these aids so the help of your family, friends and any professional therapists will be a great help, particularly in the early stages of your recovery.

Conclusion

Sometimes you won't be able to do it on your own and you may need training to be able to overcome the difficulties you may face in making the right decisions. In these circumstances it is right for you to seek the advice of an Occupational Therapist, Clinical Psychologist or Clinical Neuropsychologist. Talk to your GP about how to access further support in your area.

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 and support you through these challenges. To help you overcome some of the other difficulties you may be facing after you brain injury, Headway Nottingham have produced a series of factsheets:

- 1. About the brain and what can happen after brain injury
- 2. Difficulties with decision making after brain injury
- 3. Top tips for managing memory loss after brain injury
- 4. Strategies for mood management after brain injury
- 5. Top tips for managing depression after brain injury











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6. Coping with a lack of insight after brain injury





