

Memory Difficulties and Spinal Cord Injury

National Spinal Injuries Centre
Stoke Mandeville Hospital

Safe & compassionate care,

every time

Introduction

Some people who have a spinal cord injury also have problems which affect their memory, concentration and other 'cognitive' processes. The reasons for this are varied: for some people this is because they have also injured their head at the time of their spinal cord injury; for others this may be due to a procedure or illness that has affected their brain in addition to their spinal cord, and there are some people who have difficulties with memory or other forms of 'cognitive function' due to reasons which are not directly related to the cause of their spinal cord injury. 'Cognitive functioning' refers not only to memory but also to attention, comprehending and producing language, calculating, reasoning, problem-solving, decision-making, visual abilities and other areas of thinking.

This booklet provides information about common difficulties which may result from memory and other problems with cognitive function. There is advice on what to do if you are concerned about this during your rehabilitation stay at the National Spinal Injuries Centre (NSIC).

There is also a section explaining what help is available if there are any concerns about 'informed consent' to treatment or surrounding 'capacity' to make decisions in hospital. It is important to note that these issues do not routinely arise where memory or other cognitive difficulties occur, but when this does happen there is support.

Memory and Other Areas of Cognitive Function

This section introduces some common difficulties which may result from memory and problems with other forms of cognitive functioning.

Memory

We use our memory for things we have heard or read, and also for things we have seen, such as pictures, faces and remembering routes. A common memory problem is difficulty in remembering events. While long-term memories can usually be recalled at least in some form, recent events are much more prone to memory loss. Short-term memory loss can range from occasional forgetting of names, to the inability to remember all information after a few minutes. This can be very frightening, frustrating and upsetting, and may make it difficult for you to participate fully in day-to-day activities and rehabilitation.

Language

Problems in this area may include word finding difficulties, naming problems and difficulties in being able to make sense of what other people are trying to tell you.

Attention and Concentration

Some people notice problems with keeping their mind on tasks and following what is going on around them. For example, some people comment that they are less able to enjoy reading books or watching television programmes than they once were because it is difficult for them to keep focused.

Visual and Spatial Abilities

Some people notice problems with finding their way around, and noticing and taking on-board information in the space around them. Examples of problems in this area might include getting lost and disorientated when going somewhere, bumping into things and misjudging spaces.

Executive Functioning

The term 'executive functioning' refers to our ability to organise, monitor, initiate, problem-solve, plan, and be creative and flexible in our thinking. Executive functioning also oversees our ability to get on with others, and our emotions and behaviours. Problems in this area can affect the way we learn, how we respond to information and our behaviour in social situations. Friends and family may notice a change in how we present ourselves and in our outlook.

What to do if you are concerned

This section provides some advice on what to do if you are concerned about memory or cognitive functioning during your rehabilitation stay at the NSIC.

Talk To Your Rehabilitation Team

Tell your Consultant if you have any concerns about your memory or any other cognitive problem. You can also speak with any other professional in your rehabilitation team, which includes: nursing staff, Physiotherapist, Occupational Therapist, Case Manager and Clinical Psychologist. You can decide together whether the difficulties you are experiencing require further investigation or whether they can be monitored with you by your treating team.

Depending on the cause of the problems in this area, it is very possible that problems with cognitive functioning can improve with time. Your treating team will be able to help you to better understand the specific issues that affect you and give you some guidance on how to manage these while you are at the NSIC.

Consider requesting a formal neuropsychological assessment

The Clinical Psychologist in your team is fully trained in this area and therefore can give you advice. In some cases it might be suggested that formal tests of memory and thinking are carried out. These are paper and pencil type tests which can be used to help identify specific areas of difficulty and also areas of strength, which can be useful feedback for you, your family and your treating team. Your Clinical Psychologist can work with you to think about strategies which may be helpful to you during your rehabilitation stay.

Try out some practical strategies to help

It is important to have some strategies to help you to continue with your daily life and help you feel more in control. Everyone will have a unique combination of strengths and difficulties, and ideally strategies should be tailored to every individual. However, here is a list of some commonly used techniques which some people find helpful:

➤ **Write down** important things to remember. Some people use diaries, mobile phones, calendars or notebooks to write things down.

➤ **Create associations** to help you remember. These might include using images, acronyms or associations with familiar things.

➤ **Develop a routine.** New routines or procedures need to be frequently practised and rehearsed. Your rehabilitation team can help by breaking procedures down into manageable parts and going through the entire sequence with you regularly and consistently to begin with. Once you have learned your routine, you will have fewer things which you actively need to remember.

➤ **Allow yourself enough time** for important activities. Your rehabilitation team might suggest building rest time into your timetable in between sessions, or try out shorter sessions to start with.

➤ Ask your rehabilitation team to use **photos or diagrams** to illustrate important routines or procedures, or leaving yourself visual reminders of things you need to remember.

➤ Use an **alarm** to help you to remember to do things.

➤ **Ask other people**, including staff, friends and relatives, to help you by rephrasing things, repeating information, regularly checking that you have understood and are keeping up, and giving clear feedback to help you to monitor how things are going. It may also be helpful to ask other people to remind you about things or write things down for you that you need to remember.

- Use a **pill box** or checklist to help you remember to take medication.
- Use a **bag** on the back of your wheelchair or carry with you and have **set places** for items to help you keep important things in the same place.

Review how things are going in your Goal Planning Meetings

The above list just gives a few examples and is not exhaustive. Your treating team can help you to think about what works best for you. Every patient at the NSIC has Goal Planning Meetings, where they meet with their treating team on a regular basis throughout their rehabilitation journey. This is a good place to review how things are going for you and discuss helpful approaches to your rehabilitation as a whole team.

Informed Consent to Treatment and Capacity

All patients need to be able to give their 'informed consent' to treatment and have the 'capacity' to make decisions surrounding their care. This is automatically assumed, unless there is a specific concern raised about a particular situation where the ability of the patient to fully understand and process the pros and cons of what is being proposed is called into doubt. Should this situation arise, members of your treating team will meet with you to help support you in making decisions about your own care. It is certainly not the case that 'informed consent' and 'capacity' are questioned simply because a concern about memory or thinking is raised. Please speak with a member of your treating team if you have any concerns about this.

Concerns

If you have any concerns about the treatment and rehabilitation you receive, or about your experience at the NSIC, please raise them with a member of staff. If you are particularly satisfied about the service you have received at the NSIC, you are welcome to let us know, preferably in writing.

All NHS Trusts have a commitment to monitor and improve the quality of their services and therefore comments from users of those services are especially helpful.

How can I help reduce healthcare associated infections?

Infection control is important to the well-being of our patients and for that reason we have infection control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. We ask that you, and anyone visiting you, use the hand sanitiser available at the entrance to every ward before coming in to or after leaving the ward. In some situations hands may need to be washed at the sink using soap and water rather than using the hand sanitiser. Staff will let you know if this is the case.

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01296 315823

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