

Managing memory problems after encephalitis

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The long-term effects of encephalitis can include changes in memory, thinking and behaviour, which may greatly affect a person's ability to return to their previous level of functioning in relation to their everyday activities, social life, leisure and work. This factsheet aims to help people understand why there are memory problems after encephalitis and what can be done to help.

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1. Memory problems and the temporal lobe

The most common form of infectious encephalitis results from the herpes simplex virus. If we look at the brain of someone who has suffered herpes simplex encephalitis, it is common that there is damage to the temporal lobes of the brain. The temporal lobes are important for learning new information, forming new memories and storing memories and information over time. So, the temporal lobes are important for remembering experiences and events we have been involved with (episodic memory), as well as learning new facts/information about the world (semantic memory). This explains why memory loss is one of the most frequent and often most disabling effects of encephalitis.

Other types of encephalitis, whether viral, bacterial, post infectious or auto-immune, may also involve the temporal lobes to varying degrees with accompanying memory changes. Depending on the circuits within the temporal lobes affected by the encephalitis illness, a survivor may have difficulty with:

- remembering new information, events or experiences (e.g. details of a conversation, or a recent holiday)
- learning new things (e.g. learning how to use the new washing machine)
- remembering to do things (e.g. attend a hospital appointment or take their medication)
- remembering some things from before their illness (e.g. details of events such as family holidays, weddings).

When you are with someone who has memory problems following encephalitis, it is very important to remember that not every aspect of memory is necessarily affected. Thus, although many people will have difficulties in remembering what has happened and remembering to do things, they will usually remember people and facts they learned some time before they became ill. Overlearned skills, such as typing and swimming are usually unaffected and language also survives fairly well, although some people experience word finding problems.

A neuropsychological assessment can be useful to gain a better picture of what aspects of memory and other cognitive skills have been affected by encephalitis, and to then develop a rehabilitation plan to help manage everyday problems.

2. Practical steps in managing memory problems

There are several straightforward practical steps that can support the everyday activities of someone with memory problems after encephalitis. It is important that strategies are matched to the needs of each person as not all strategies will be needed for everyone. Below are some practical strategies that can be useful:

- Use a diary and written notes to remember future events and to recall what has happened in the recent past. This may be a paper diary, or it could be an electronic diary on a mobile phone. A mobile phone has the advantage of being able to alert you that something needs to be done.
- Use a prominent wall chart to indicate the date and any events that are taking place that day/week. Effective use of this wall chart can reduce the amount of repetitive questioning that sometimes occurs when people have a memory impairment. It can also increase self-reliance and confidence.
- Organise the environment so it is structured and uncluttered; keep things like keys, wallet etc., in the same places as much as possible. This will make it easier to learn where things are and so less likely they will be lost. Put a flow chart on the wall giving instructions about which places to look for things if the person habitually misplaces them (e.g. glasses).
- Use labels on doors to indicate where household things are located (e.g. which cupboards are for crockery, food etc.).
- Place a written sign by the front door, such as 'don't forget your phone' to remind a person to take items with them as they leave the house. Motion sensitive reminders can be purchased to provide an audio reminder to take belongings.
- Try to maintain a regular routine. This helps the person with a memory problem to learn when to do things and so do things without the need to be reminded.
- Try to make things/places distinctive if the person has problems finding them. The toilet, for example, can be made easier to find by painting the door a different colour to the other doors. Alternatively, the path to it can be marked with distinctive masking tape.
- Display photographs of family and friends prominently and label them with their names.
- A wide range of aids are available to help people remember to take medication.

The above are all things you can do without any specialised help but more is possible if you seek the professional help of a psychologist or occupational therapist who is able to help by matching an individual's memory needs with available compensatory aids and strategies.

3. Assistive technology

The use of memory aids seeks to improve a person's ability to do the things that are important to them in everyday life, in spite of having a memory problem. Increasingly, assistive technology is available that can be used to compensate for memory difficulties. This approach acknowledges the memory problems and then attempts to work around the problem to improve a person's ability to do things independently. A number of technological aids are available such as:

- Smart phones are very much part of everyday life. In addition to making calls or sending text messages, most smart phones have a calendar, diary, contacts list and alarm function. You can also use a voice recorder to record a voice note about something you want to remember for later. Many phones will synchronise with a home-based computer to access information and reminders. There are an increasing number of apps with the potential to support people with memory problems to remember past events or what they have to do at a future time. Sometimes the person with memory difficulties may need additional training to learn how to use their phone to support their memory in these various different ways.
- Smart watches can be used to prompt a person to do things, including consulting a daily schedule (e.g. at 11 am put the oven on for lunch) to check they are on track or to monitor their fatigue. These devices typically only display limited information and thus require a degree of specialist training to maximise benefit.
- Smart speakers/voice assistants (e.g. Alexa; Google Home; Siri) can also be useful as they can also be programmed to provide reminders and provide access to a wide range of useful information.
- 'Pill reminding' devices include medication boxes with alarms.
- Motion-activated reminders are devices which enable you to record a message that is played when a person walks into the area of the device, such as reminding you to lock the door when you leave and to take your keys when you leave the house.
- Locator devices are small electronic tags that help you to locate items such as keys, wallet if they are mislaid.

Memory aids have great potential to support the everyday functioning of people with memory problems following encephalitis. Specialised training and support in how to use memory aids to address specific memory difficulties is recommended to ensure consistent and long-term use. A clinical neuropsychologist, clinical psychologist or neuro-occupational therapist can help train the use of a range of memory aids to meet individual needs.

4. Using memory more effectively

Unfortunately, memory is not like a damaged muscle that can be made strong again just by exercising it. Memory loss arises because brain cells, connections and systems have been irreparably damaged and repeated practice or drills do not restore memory function. Memory games and exercises can sometimes be useful for people with memory difficulties to get to know more about the strengths and weaknesses of their memory, and to learn how particular strategies can help to make better use of their remaining memory functions. It is just that simply exercising memory repetitively by doing memory games is unlikely to improve memory functioning. There are a number of strategies that can help people remember information more efficiently. For example, it has been shown that people can improve their memory for information by using certain study techniques or remember faces by developing a mnemonic which includes the person's name and a prominent facial feature. It can be difficult for people with memory problems and other cognitive problems to know how to use these strategies without assistance, so it may be helpful to seek assistance from an occupational therapist or neuropsychologist, or family members.

5. Errorless learning

Until recently, people with memory impairments were often encouraged to guess if they didn't know the answer to a question. However, new research suggests that this isn't always effective, as they are more likely to remember their incorrect guesses than the correct answers. This has led to the development of "errorless learning," a method where the person learns information in ways that reduce the likelihood that they will make errors during the learning process. Studies worldwide show that this approach helps people learn skills like remembering names, directions, and using a new piece of technology. Evidence strongly suggests that preventing errors during the learning improves learning in those with severe memory issues, though it is also important to for people to practice recalling the information they are trying to learn. Certain techniques, such as 'spaced retrieval' and 'vanishing cues' can give a good balance between reducing the chances of making errors while learning something new, whilst still giving opportunities to recall the information. The key takeaway is trying to avoid errors when learning new information but ensure there are opportunities to practice recalling the information being learned.

6. Memory groups

In these groups people often try out new strategies for remembering things, gain information about memory function, and generally discuss their problems. There is evidence that people attending memory groups gain support and have a more positive mood even when there is no direct change in their memory ability. The group provides an environment where people can discuss problems with others who understand from first-hand experience the specific difficulties encountered. The participants experience feelings of relief when they discover that their problems, both memory and emotional, are shared. Another benefit is that that strategies and advice may be better received coming from other survivors than from carers or medical professionals.

Conclusion

Whether you are memory-impaired or a carer we hope this factsheet has given you some encouragement about coping with memory difficulties. Much of what we have said involves things you can do for yourself. Working with a clinical neuropsychologist or occupational therapist can also help to improve everyday function.

FS026V5 Managing memory problems after encephalitis

Date created: June 1999; Last updated: December 2024; Review date: December 2027

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