

Managing memory problems after encephalitis

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The long-term effects after encephalitis may be characterised by cognitive and behavioural changes which may have a significant impact upon psycho-social functioning and return to an individual's previous level of functioning. 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 almost inevitable that there are some damages to the temporal lobes of the brain. It is well-established that the temporal lobes are actively concerned with forming new memories (a process known as consolidation) and storing memories. Temporal lobe systems are also responsible for remote memory and semantic memory (our facts and understanding of the world). This explains why memory loss is the most frequent and often most disabling effect of encephalitic illness.

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 remembering new information (e.g. the name of his or her doctor, details of a conversation)
- what they have to do (e.g. attend a hospital appointment or take their medication)
- events before their illness (e.g. family holidays).

Confronted with someone who has memory problems following encephalitis, it is very important to remember that not every aspect of memory is affected. Thus, although most people will have marked difficulties in remembering what has happened and what is going to happen, 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 cognition have been affected by encephalitis, to then develop a rehabilitation plan to 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 post-encephalitis:

- 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.
- 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.
- Use a diary and written notes to remember future events and to recall what has happened in the recent past.
- 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.
- 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). Organise the environment so it is structured and uncluttered; keep things in the same places as much as possible. This will enhance the possibility of the person learning where things are.
- Try to maintain a regular routine. People with memory problems may become quite unsettled if these routines are interrupted.
- Display photographs of family and friends prominently and label them with their names.

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. Memory aids

The use of memory aids seeks to improve everyday memory function by compensating for changes in memory function. This approach acknowledges the memory problems and then attempts to work around the problem to improve independence. 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. Some will synchronise with a home-

based computer to access information and reminders. There are also both Apple and android operating systems for the provision of numerous 'apps' with great potential to support people with memory problems to remember past events or what they have to do at a future time. However, these functions may be quite complex and require additional training to help support memory problems.

- Watches that beep every hour can be used to prompt a person to consult 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.
- 'Pill reminding' devices include medication boxes with alarms.
- A pager called NeuroPage has been shown to reduce the everyday problems of many memory impaired people. With the collaboration of the person with memory problems, a personal reminder is sent to a portable pager at set times throughout the day.

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 is able to help train the use of a range of memory aids to meet individual needs.

4. Using the remaining memory more effectively

Memory is not like a damaged muscle which, with appropriate exercise, can be made strong again. Memory loss arises because brain cells, connections and systems have been irreparably damaged and repeated practice or drills do not restore memory function. A different approach is to try and teach the person strategies for using their remaining memory abilities more effectively. There are strategies to help people remember some information more efficiently capitalising on the fact that people learn things more quickly when using these strategies than when simply repeating things without a strategy. Thus, it has been shown that people can improve their memory for text by using particular study techniques or remember faces by developing a mnemonic which includes the person's name and a prominent facial feature. As noted above, it can be difficult for people with memory problems and other cognitive problems to know how to use these strategies spontaneously. Thus, it is often family members or therapists who work through these strategies or mnemonics.

5. 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.

6. Memory and the use of a computer

While strategies may be of some help many psychologists believe that memory rehabilitation can only be effective if it targets specific needs. One area, in particular, is that of learning to use a computer. Recently a number of studies have shown that even severely impaired people can be taught how to use computers and, in some instances, this training has enabled the person to resume employment. At first, it might seem paradoxical that someone who is unable to remember anyone's name should nevertheless learn to operate a computer. The explanation is that learning how to use a computer partly relies on a form of memory that is usually unaffected by brain damage. Thus,

although learning is slower, and less comprehensive than that obtained by non-injured people, it can proceed to a point where the person has acquired enough knowledge to work independently. Training will require support from a specialist clinical neuropsychologist or neuro-occupational therapist and can be time consuming.

7. Errorless learning

Up until recently it was usual practice to encourage a memory-impaired person to guess if they did not know the answer to a question. Recent research does, however, question this approach because what happens is that the person tends to keep remembering their incorrect guess rather than the correct answer. This has given rise to a form of training which is called 'errorless learning'. In this training the person is exposed to the answer a number of times before being asked to remember it thus greatly reducing the possibility of an error being generated. Studies in many countries have shown the method to be effective for teaching people to remember names, directions, how to operate a personal organiser and other skills. There is strong evidence that avoiding errors during learning leads to better learning in people with severe memory problems so the basic message is clear: if you are trying to teach a memory-impaired person something, avoid them making errors at all costs. We can only benefit from our mistakes if we can remember the mistakes.

Similarly there is growing evidence that repeated practice is helpful to learn new information if this is done over a number of days in a practical manner as opposed to attempting to cram new information.

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.

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