

Memory and epilepsy

A self help guide for improving memory functioning
in people with epilepsy



Produced by Epilepsy Action in association with the University of Liverpool.
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Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work...

- We provide information to anyone with an interest in epilepsy.
- We improve the understanding of epilepsy in schools and raise educational standards.
- We work to give people with epilepsy a fair chance of finding and keeping a job.
- We raise standards of care through contact with doctors, nurses, social workers, government and other organisations.
- We promote equality of access to quality care.

Epilepsy Action has local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

Join us...

You can help us in our vital work by becoming a member. All members receive our magazine *Epilepsy Today*, free cover under our unique personal accident insurance scheme and access to our services and conferences.

“ Our vision is to live in a society where everyone understands epilepsy and where attitudes towards the condition are based on fact not fiction ”

Epilepsy Action, vision statement

Contents

Introduction	4
What is memory?	4
What causes memory problems?	5
Memory difficulties in people with epilepsy	6
How are people with memory problems affected?	8
Neuropsychological memory assessment	9
Memory enhancement strategies	10
Specific memory problems	14
Remembering to do something	15
Remembering people's names	16
Remembering where you have put something	18
Remembering what people tell you	18
Remembering what you are reading	20
Remembering how to get somewhere	21
Summary	21
Hints for helpers	23
Further information	24
How to contact us	27



Introduction

A self help guide for improving memory functioning in people with epilepsy.

It is widely recognised that people with epilepsy commonly complain about memory problems. This booklet, written by Professor Gus Baker and colleagues at the University of Liverpool, is a clear self-help guide to memory problems in people with epilepsy. It explains the difficulties that can be faced and provides simple strategies that may help the individual to overcome them.

What is memory?

Memory is the ability to recall past experience and knowledge. It is divided into short-term memory (STM) and long-term memory (LTM). Short-term memory deals with information that is to be remembered over a period of a few minutes, and long-term memory deals with anything that is to be remembered for longer than this.

Recording the memory in the first place is called encoding. The information is then passed from short-term to long-term memory for storage. Long-term memory is divided into three types.

Procedural memory	Semantic memory	Episodic memory
Activities which are carried out almost without thinking, for example, riding a bike.	Knowledge that has been acquired but we are not sure when, for example, capital cities.	Personal memories of everyday life.

Memory can also be divided into verbal and visual. Verbal memory is the ability to remember information which is perceived aurally, for example, words and sound. Visual memory is the ability to remember information that is provided visually, for example in terms of pictures and faces.

When we want to remember something, the information we need is brought back from long-term memory to short term memory. This is called retrieval.

If we have forgotten something it could be due to problems with:

- recording the memory in the first place (encoding)
- the storing of the memory (storage)
- recovering the memory from LTM (retrieval).

What causes memory problems?

Everybody will experience some minor lapses in memory. These can occur when we are:

- under stress
- trying to concentrate on a number of things at once
- feeling unwell
- feeling tired.

Also, as we get older, lapses in memory can become more common. This variation is perfectly normal and nothing to be concerned about.

However, memory problems can be much more pronounced and long-term. They can be caused by a number of things, for example:

- a dementia type illness such as Alzheimer's disease
- an infection of the brain, for example encephalitis
- a shortage of oxygen to the brain, as in cerebral palsy
- head injury
- certain types of stroke
- a brain tumour or brain haemorrhage
- epilepsy, on its own or with one of the above.

Memory difficulties in people with epilepsy

The presence of memory difficulties in people with epilepsy is well recognised. In fact people with epilepsy seek help for memory problems more often than for any other impairment. Research has shown that a large portion of memory is located in a specific area of the brain known as the temporal lobe.

Temporal lobe

There are a number of reasons why people with epilepsy may have memory difficulties.

- Epileptic seizures can affect memory functioning because, in order for memory to work properly, the brain needs continuous self-monitoring. This self-monitoring system can be disrupted during a seizure. Memories before a seizure can be lost, as they have not been fully incorporated into our memory system. During a seizure our memory may also be affected, because a loss of consciousness can interfere with normal brain processes, disrupting the encoding and storage of information. The confusion that can occur following a seizure can also



prevent our memory from working properly. Some people with epilepsy can experience unusual electrical activity within the brain between seizures and this can also affect attention and memory functioning.

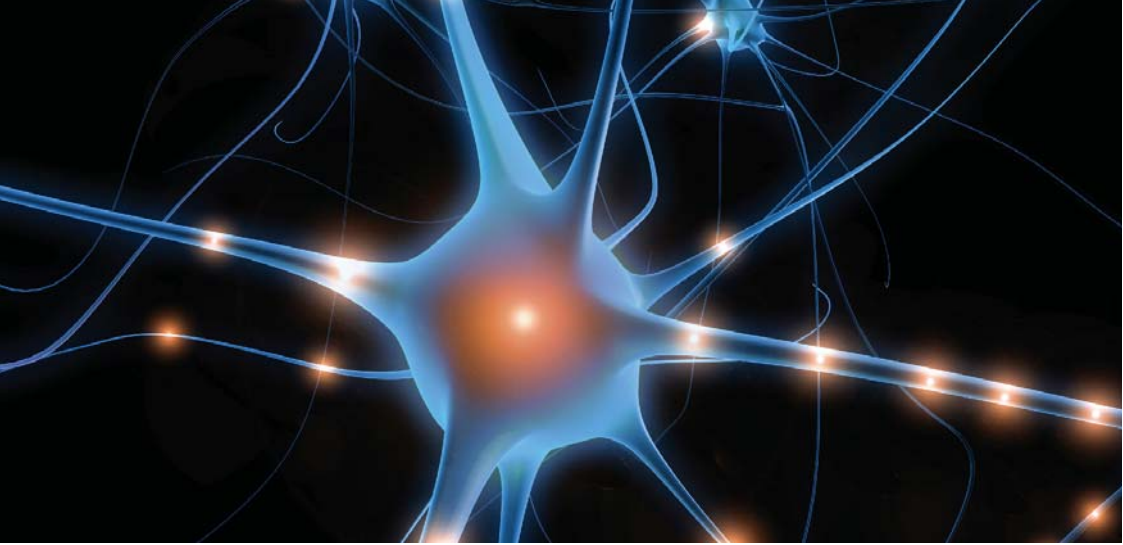
- An underlying brain tumour or lesion can disrupt the memory process. Therefore if a tumour or lesion is located in the temporal lobe, which is a part of the brain needed for memory, this may also cause memory problems.
- Some anti-epileptic medications may interfere with memory functioning as they can affect the speed at which the brain can process information. On the other hand they also reduce seizure frequency and, as we have discussed, frequent seizures can also cause memory impairment. If you are worried your medication may be affecting your memory, it is important to speak to your doctor about your concerns. They can investigate this possibility and will discuss possible solutions with you.

It is worthwhile noting that the cause of some of our memory problems may be due to another problem, which is resulting in impairment in memory. Here are some examples.

- **An attention problem.** If we do not pay attention to the information we are presented with then this information is not recorded by our memory.
- **A language problem.** Sometimes in conversation we find it hard to find the word that we are looking for. This can be misinterpreted as forgetting words.
- **A visual/spatial problem.** People can have difficulty working out where they are in relation to other places or objects and therefore can experience difficulty in working out how to get somewhere.
- **Anxiety and depression.** People with an altered emotional state often experience memory difficulties. Those who experience anxiety can find their mind is too occupied with worrying thoughts to concentrate on things around them. Those who are low in mood can also feel lethargic and low in motivation, therefore lacking the attention needed to record a memory.
- **Sleep disturbances.** If we are not getting enough sleep then we can experience difficulty concentrating, which again disrupts our attention to information.

How are people with memory problems affected?

Memory problems can affect people in different ways. It may be that a person's memory problems are very general, and will therefore affect most areas of memory functioning. However they can also be very specific and might only affect one aspect of memory functioning, such as remembering what people tell you.



Memory problems can cause a range of difficulties, making it difficult to cope with everyday living and relationships. These difficulties can cause a great deal of distress for the person affected. However, while a memory problem cannot be cured, it is possible to adapt to having a memory impairment, making it easier to cope and live a relatively normal life.

Neuropsychological memory assessment

In order to get an accurate assessment of your memory function, the doctor may suggest carrying out a neuropsychological assessment. Neuropsychological simply means looking at the processes that the brain carries out, one of which is memory. This assessment aims to get an accurate idea of how well your memory is currently functioning and will be carried out by a psychologist. It will look at all areas of your memory ability. More specifically it will be looking at your ability to remember pictures, stories and numbers. Through looking at these areas, the psychologist will be able to discover where your memory difficulties lie and if there is any difference between your:

- visual memory (your ability to remember pictures); and
- verbal memory (your ability to remember information presented orally).



This information then provides some focus on which memory enhancement strategies are going to be the most helpful to you.

Memory enhancement strategies

It is possible to find ways of adapting to living with memory problems. Various methods can be used to help people with memory problems store and recall memories more effectively. Possible ways of doing this are:

- following a set routine
- adapting your surroundings
- using external memory aids
- using 'mnemonics'
- improving general well-being.

Strategies can be combined to help you adapt to living with memory problems.

The following section will outline these strategies in more detail. It is likely to take some time to get used to using the various strategies which can help to enhance your memory. There may be some 'trial and error',

and it will require effort on your part. However, experience has shown that, once incorporated into your lifestyle, these strategies can be extremely effective and beneficial. It is worth noting here that the key to making these strategies work effectively is organisation and establishing a routine, as this reduces the demands placed on your memory.

Following a set routine

It cannot be stressed enough how important following a routine is to improving your memory. Having a routine means you can get used to what to expect, which helps reduce the demands placed on your memory. A lot of people find it useful to make a note of their regular activities in their diary or on the calendar. Also, always doing things at certain times of the day, for example always taking medication with breakfast can help some people.

Adapting your surroundings

By adapting your surroundings you will have less need to use your memory, and therefore this reduces the difficulties you can experience. This can be achieved in a number of ways:

- keeping a note pad by the phone to take messages
- using a notice board for important information
- having a particular place to keep things, such as keys and glasses, and always putting them in the same place
- labelling cupboards to remind you what goes in them.

People around you can help with this by altering how they do things, or how they respond to you as a person with a memory impairment.

Using external memory aids

There is a wide range of external memory aids and the most important thing is to choose something that you feel comfortable with. What suits one person may not necessarily suit another. For example, pictures or diagrams may be more useful for people who find reading difficult.



Bread
Eggs
Soap
Tea

Possible memory aids

- diary/calendar
- notebook
- lists, for example shopping lists
- alarm clock or timer
- mobile phone with alarm
- wall chart or wipe clean memo board
- tape recorder or Dictaphone
- electronic organiser
- electronic pager
- pill reminder box for medication
- Post-It notes
- photo album or memory book.

Getting used to a new memory aid can be quite demanding and it may take you a little while. However, the more you use a memory aid the easier it will become to incorporate into your everyday life. Eventually it will seem like second nature.

It can be easier to use memory aids that you are more familiar with, for example, if you like using modern technology then you may find personal organisers and computer diaries work for you. However, if you are not keen on computers, pen and paper methods such as diaries and calendars may be easier to use.

Mnemonics

A mnemonic is a verbal or visual aid which helps us to remember information, usually in the form of sayings, rhymes or pictures. For example to remember the colours of the rainbow some people use the rhyme:

Richard **O**f **Y**ork **G**ave **B**attle **I**n **V**ain
Red **O**range **Y**ellow **G**reen **B**lue **I**ndigo **V**iolet.

Some people find visually pairing items can be useful; one such method is known as the peg method. 'Pegs' are used to help you to remember a list of items. Each number is given a rhyming visual cue – 'one - bun, two - shoe, three - tree, four - door etc. Using this method you would visualise the first thing you want to remember and associate it with a bun. Other people try to remember information in the form of a story they have made up. These are only suggestions of methods you could use. Often the best thing is to be imaginative and make up ones that are personally relevant and work for you.

Combining a variety of strategies to enhance memory

People with memory difficulties can often find it helpful to use several aids or strategies, so that if one method fails there will be another one as a back-up. Writing on the calendar and using an alarm to remind you of an appointment is one example. It can take time to establish a memory system but, once it has been set up and is used frequently, it can be very effective.

Improving well-being

Living with memory problems, you may often feel vulnerable and unsure of yourself. Given the practical difficulties of memory problems you may experience some anxiety. Anxiety management and the use of relaxation techniques can therefore be beneficial. Your GP will be able to give you advice on where you can get information on this.



Factors causing a reduction in well-being can include a loss of structure to your daily routine (for example losing your job) or a general loss of independence, status or role. This can be exaggerated if it is accompanied by other factors, such as an inability to drive and a dependence on others. Improvements in well-being can be achieved in a number of ways, for example through developing new activities or hobbies. It can also be helpful to talk to others experiencing similar problems and to find out if there are any organisations or support groups in the area that may be useful.

Specific memory problems

Some of the most common difficulties people with memory impairments can experience are:

- remembering to do something
- remembering people's names
- remembering where you put something
- remembering what people tell you
- remembering what you are reading
- remembering how to get somewhere.

Positive Action



Epilepsy Action is a membership-based charity. To provide our vital services to people who live and work with epilepsy, we rely on membership subscriptions and donations.

Standard membership costs from £17 a year. For that you will receive the following items.

- Six copies a year of our specialist epilepsy magazine *Epilepsy Today*, packed with current news and articles, personal stories and letters.
- £1,000 worth of FREE accident insurance and the opportunity to buy further cover at a reduced rate.
- Access to our online memberZONE where you can download back copies of our magazines and see exclusive articles, stories and news.
- Access to our wide range of epilepsy resources – information leaflets, books, videos – many of which are free or discounted to members.
- Reduced entrance to our conferences around the country.

Professional membership costs only £45 a year. As well as the above you will receive four copies a year of *Epilepsy Professional* and eight of *Seizure – The European Journal for Epilepsy*. You can also choose a free manual on either Health Care, Education or A Practical Guide.

To find out more about the benefits of becoming a member call us on 0113 210 8800 or email membership@epilepsy.org.uk. To join us please complete the form overleaf and return it to us at Epilepsy Action, FREEPOST LS0995, Leeds LS19 7YY.

Supporting Epilepsy Action



Epilepsy Action relies on public support to fund our vital services and there are many ways you can help. So why not get involved?

For further information on any of the ways of giving or taking part in events, just tick where you'd like further information and we'll send you out a pack.

- Leaving a gift in your will
- Making an in-memorial donation
- Payroll giving through your company
- Events - from climbing Ben Nevis to trekking up Macchu Picchu to drinking tea and eating cakes. There really is something for everyone.
- Corporate team events
- Ordering our cards, gifts or branded merchandise
- Selling our raffle tickets

Information on all of the above and a great many more ideas is available on our website. Alternatively call us on 0113 210 8800 or email funding@epilepsy.org.uk.

Many thanks indeed for your support!



The following section will outline how these problems can be made easier to cope with and which strategies will work well for particular problems. These are only suggestions to give you an idea and you may think of others that you find more useful.

Remembering to do something

- Leave things in your front hall before you go out, for example, letters you need to post.
- Watches or organisers can be programmed to sound an alarm at certain times to remind you to do something.
- If possible, do things immediately rather than later on.
- Keep a pen and paper handy at all times.
- Use diaries, wall charts and calendars.

People often forget if they have done a particular task (such as locking the door). A way to improve this type of memory is to say out loud what you are doing at the time you are doing it.



Remembering people's names

Recording the information

1. Listen carefully.
2. If the name is unusual, ask them to spell it.
3. Think about whether you like the name or not.
4. If you're introduced to several people, make an excuse to repeat back their names, for example "Let me make sure I've got your names right..."
5. Try to use the name as often as possible in your initial conversation, for example "Glad to meet you John". When you say goodbye, repeat the name.
6. Repeat the name after a short interval. And remember, most people enjoy hearing their name being spoken.

7. If it's a foreign name, alter the way it sounds to make it more meaningful to you.
8. Split a long name into shorter words.
9. Some names may be easy to pair with a visual image, for example, Mr Butcher.
10. Form a link between the person you meet and someone you know with the same name, or a famous personality. Try to find some similarities.
11. Keep rehearsing the names you learn every few hours or days.
12. Try associating the name with a prominent feature on the person's face.

Recalling the name

1. Try not to panic!
2. Think through each letter of the alphabet in turn to see if it triggers your memory for the person's name.
3. Think of the situation where you first learned the name, and anything about the situation that you may have linked with the name.
4. Say something like "I remember you very well but your name has just slipped my mind for the moment".
5. Shake hands and say your own name; they may instinctively repeat theirs. If all else fails, you can often chat without saying their name.

Remembering where you have put something

1. Try to be well organised. Spend a little time each day putting things back that you have put out of place. Set specific places for things.
2. Make a list of things that you lose quite often and make a special habit to put them back in the right place.
3. Stop and think each time you put something away. Concentrate for a few seconds and look at the particular place you put them.
4. Find a connection between the object and the place that you are putting it. For example, if you put your keys in a cup, imagine yourself drinking with a large key in your hand rather than a cup. This should help you when you try to remember where you put the key.
5. When you park the car, try to park it near the exit or near a ticket machine, and then look at it a few times as you walk away and concentrate on where you left it.
6. Once you have put something away try to think of it, and where you have put it, at intervals afterwards. Try to make the intervals a little longer each time.

Remembering what people tell you

1. Write the message down. It is useful to do this in an organised, meaningful way. You could make parts of the message stand out by writing in a different colour or underlining.
2. Try to think about what you are hearing, for example do you agree or disagree with it?
3. When trying to remember numbers, group them together, for example



2-7-4 could be remembered as two hundred and seventy four.

Telephone numbers can be remembered in a similar way. Or try to find a meaning to the number. For example 2-7-4 could be somebody's birthday (27th April) – the 27th of the fourth.

4. In the case of a list of things someone has asked you to do or buy, it can be helpful to try and associate items in the list with each other. This can be achieved by grouping certain items together, depending on a category they belong to or maybe using the first initial of each item to make up a word. So to remember to get bread, eggs, sugar and tea use the word 'best'. It may also be useful to associate this word with the place that you are going, so you could imagine George Best playing football in the aisles of your local supermarket. More unusual associations are usually more likely to stick in your memory.
5. If you have forgotten a message then try to remember details about it, such as who gave it to you, where you were when you got the message and what you were doing at the time. This may jog your memory.



Remembering what you are reading

1. In general, it is useful to try and group the material that you are reading into subheadings and then go over the subheadings each time you read the material.
2. Use a highlighter pen to colour important sentences.
3. Test your recall about the information you have just read and repeat this at certain intervals.
4. Read through the material again and concentrate on the information you have forgotten.
5. The PQRS method can be used to help you remember information that you are reading.

Preview	Skim through the information to get a general idea about what is being said.
Question	Decide upon questions you want to be able to answer once you have read the information and write them down.
Review	Re-read the information.
State	Sum up the most important points.
Test	Test yourself by seeing if you can answer the questions that you set for yourself earlier.

Remembering how to get somewhere

1. Plan your journey and use a clear map or directions. Decide if you are happier with a map or written instructions.
2. Make a note of any landmarks you will be passing on the way.
3. If you get lost don't panic. Try to go back through your directions and spot where you have gone wrong.
4. Take a telephone number of someone who could help you should you get lost, and remember you can always ask someone in the area for help.

Summary

Be organised

- ✓ Keep a fixed routine, with set things at set times of the day.
- ✓ Be well organised – have a place for everything and have everything in its proper place. Use labels if necessary.



General advice

- ✓ Get a good night's sleep and do difficult jobs when you're feeling fresh and there are not too many distractions.
- ✓ Try not to do too many things at once. Do major activities one bit at a time.
- ✓ Try to stay calm and avoid stressful situations. If you forget to do something, don't get too upset about it. Try to keep things in perspective.

Better ways of remembering

- ✓ If you have to remember something, go over it in your mind at regular intervals.
- ✓ Try to find meaning in things you have to remember – use mnemonics and make associations.
- ✓ If you cannot remember something, try thinking about associations that might jog your memory.

Hints for helpers

This booklet has been written primarily for someone who has epilepsy and memory problems. If you are close to someone who has epilepsy and memory problems, it may help to improve your understanding of the difficulties they face and how they might handle them. You can help, whether you are a close relative, friend or work colleague, by following these simple guidelines:

Do

- ✓ Try to understand what their difficulties are.
- ✓ Be a bit more patient than usual.
- ✓ Support them by accepting the ways that they try to cope with their memory difficulties.
- ✓ Adapt your way of relating to them.

Don't

- ✗ Patronise or do everything for them.
- ✗ Make too many demands or have high expectations that require a great deal of memory recall.
- ✗ Tidy up or put things away if that disrupts their way of coping.
- ✗ Interrupt them when they are talking or concentrating on something.

Further information

If you have any questions about epilepsy, please contact the Epilepsy Helpline, freephone 0808 800 5050, email helpline@epilepsy.org.uk, text 07797 805 390 or visit our website www.epilepsy.org.uk

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Please contact the Epilepsy Helpline to request your free information catalogue.

Information is available in the following formats: booklets, factsheets, posters, books, videos, DVDs and CDs.

Information is also available in Braille and large text.

Epilepsy Action's support services

Local meetings: around 100 local branches offer support across England, Northern Ireland and Wales.

Volunteers: these are local people (usually with epilepsy or with a family member who has epilepsy) who have been specially trained by Epilepsy Action to give advice on a one-to-one basis. They can also give presentations about epilepsy to groups of people.

forum4e: our online community provides an opportunity to contact other people with epilepsy from all over the world, in a safe and secure website: www.forum4e.com (For ages 16 years and over.)

Live online advice: we run regular advice forums, where trained advisers answer your epilepsy questions live on our website. For more details, visit www.epilepsy.org.uk/liveadvice

If you would like more information about any of these services, please contact the Epilepsy Helpline or visit our website.

Memory and epilepsy

Please complete this form to tell us what you think of this publication.

How useful have you found this publication?

- Very
 Fairly
 Quite
 Not at all

Is the language clear and easy to understand?

- Very
 Fairly
 Quite
 Not at all

Does this publication cover all you want to know about the topic?

- Completely
 Almost
 Not at all

What do you think of the design and general layout of this publication?

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 Fairly Good
 Poor

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“ Our vision is to live in a society where everyone understands epilepsy and where attitudes towards the condition are based on fact not fiction ”

How to contact us

Telephone the Epilepsy Helpline freephone **0808 800 5050**

Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm

Our Helpline staff are Typetalk trained

Fax your enquiry to us free of charge on **0808 800 5555**

Write to us free of charge at **FREEPOST LS0995, Leeds, LS19 7YY**

Email us at **helpline@epilepsy.org.uk** or visit our website:

www.epilepsy.org.uk

Text your enquiry to **07797 805 390**

About the Epilepsy Helpline

In partnership with the organisation Language Line, the Helpline is able to offer advice and information in 150 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell them what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people's cases on their behalf.

Our staff are trained Advice and Information Officers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

We welcome comments, both positive and negative about our services.

To ensure the quality of our services we may monitor calls to the helpline.

The logo for Epilepsy Action, featuring the word "epilepsy" in white lowercase letters on a blue rectangular background, followed by the word "action" in pink lowercase letters on a pink rectangular background.

Epilepsy Helpline:

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