

Coping with thinking difficulties (cognitive impairment)

Living with a brain tumour



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CARE CAN'T WAIT

If you'd like to talk to someone about how you're feeling, or would like to find out where you can get further support (including details of support groups), you can contact The Brain Tumour Charity's Information and Support Team:

Phone: **0808 800 0004**

(free from landlines and most mobiles)

Email: support@thebraintumourcharity.org

Live chat: thebraintumourcharity.org/live-chat

Website: thebraintumourcharity.org/getsupport

Closed Facebook groups: bit.ly/FBSupportGroups

Are there treatments for thinking difficulties (cognitive impairment)?

While there's no simple cure for thinking difficulties (sometimes called cognitive impairment), your healthcare team can work with you to help improve your cognitive functioning or develop coping strategies that will help you to live independently.

For example, if you're having seizures, your health team can help reduce the effect of the seizures themselves by working with you to find the AED that works best to control your seizures. Similarly, they will select an AED that's less likely to add to your cognitive burden.

Dosages of medications, such as steroids, can also be altered if they're believed to be causing additional cognitive effects or making existing effects worse.

Your healthcare team can also identify whether your problems are made worse by other underlying factors, such as depression or anxiety, and help to address these.



How can I cope with my thinking difficulties (cognitive impairment)?

Cognitive impairment, such as a decline in memory, attention, executive function and processing speed, can have a huge impact upon your ability to carry out daily tasks and, therefore, affect your quality of life.

It can affect your personal relationships, your leisure activities and your work. In addition, fear of future cognitive decline may also negatively affect your quality of life.

It's not unusual to feel frustrated, defensive and embarrassed about the changes in some of your abilities. But there is help available.

Speak to your health team if you have concerns as they'll be familiar with your specific diagnosis and circumstances. You can also ask to be referred to a neuropsychologist or other specialist.

With some of the effects, you may be able to do things yourself to help minimise their impact on your daily life.

On the next pages are some suggestions that you may find useful depending on which sort of cognitive impairments you're experiencing and how severely they're impacting your daily life.

General coping strategies

The following is a list of things that people with brain tumours have found useful to help with their thinking difficulties, .

Find the one(s) which work best for you.

- **Plan and make lists**

You may find it useful to sit down and plan your day at the start of each day. You can then make a 'to do' list to help you stay focussed and to remind you of what you should be doing.

- **Get into a routine**

Carry out particular activities, e.g. shopping, on the same day each week; and establish routines for daily tasks, such as getting ready in the morning.

- **Break tasks down into small chunks**

Break a task down into manageable chunks with breaks in between, and only do one thing at a time.

Try not to put yourself under pressure to complete a task right away, especially if you're feeling tired.

Don't be afraid to put it away and return to it later.

And don't rush - try to pace yourself.

Set goals or targets and reward yourself when you reach them, e.g. with a cup of tea.

- **Use prompts**

When working through a task, some people find that it helps to say out loud what you're doing as you go along to keep track of where you are.

Use other prompts to monitor what you're doing, e.g. use a timer when cooking, or a pill reminder for your medication.

- **Make receiving information easier**

If someone is giving you information, ask them to keep it simple. You may also wish to write it down and repeat it back to them to check that you've fully understood.

To make it easier to concentrate, try to remove background noise, for example, by switching off the television.

- **Use memory aids/techniques**

Carry a notebook, iPad or other mobile device to note down details about people, places and arrangements you've made in order to remember the information.

Keep notepads or noticeboards around the house, e.g. by the phone or on the kitchen wall.

Use other memory aids, such as alarms, diaries, mobile phones, etc. Some people find it useful to use photos showing the stages of tasks to work through. Repeat and rehearse information to yourself throughout the day.

Link new information to pictures or stories in your head - the sillier, funnier or more unusual, the better, as they'll be easier to remember.



For more information, see our *Memory and brain tumours* webpage/fact sheet.

thebraintumourcharity.org/memory-difficulties/

- **Talk to others**

Talking to those close to you about how you're feeling and the difficulties you're experiencing can be very helpful. People will want to support you, and it can be helpful for them to have an understanding of your difficulties, so that they can show you patience and provide appropriate support.

Let others know when you're having difficulties, e.g. if you're struggling to concentrate during conversations - they may be able to help you.

- **Do something relaxing each day**

Being more relaxed can improve concentration.

- **Get enough rest**

If you feel tired, take a break and have a nap. Plan time for this throughout the day, especially if you have tasks that you need to do that day.

- **Pace yourself and reduce distractions**

- **Try to achieve a regular sleep pattern**

- **Reduce alcohol intake**

- **Try to manage your stress**

Activities, such as meditation, mindfulness or yoga, can help with this.

If the cognitive impairments you're experiencing are really interfering with your everyday life, talk to your healthcare team about it. Ask to be referred to a neuropsychologist for an assessment to look at alternative, or more specific, coping strategies.

How is cognitive impairment assessed?

Cognitive impairments are assessed by a trained health professional, such as a neuropsychologist or clinical psychologist. You have to be referred for an assessment by a member of your health team, e.g. your GP, your consultant or your CNS (Clinical Nurse Specialist).

A neuropsychological assessment can help to understand more about your cognitive functioning and wellbeing and plan ways to help you. They are NOT medical assessments, i.e. they are non-invasive tests.

After an initial appointment to discuss the difficulties you're having, you'll be given an appointment for the neuropsychological assessment itself.



Neuropsychological tests involve completing puzzles and tasks, such as copying drawings, recalling lists of words, solving a few problems or reading.



It's important to know that most people do not complete all the tasks.

Information is often also collected from friends and family, as you may be unaware of the difficulties, or their extent, because of your cognitive impairment.

The assessment can take 2 or more hours, so you may need more than one appointment to complete your assessment.

Once completed, how you did on the tests will be analysed and you'll be invited back for a feedback appointment to discuss the results and look at relevant coping strategies.

About this information resource

The Brain Tumour Charity is proud that all of our health and social care information is produced using processes accredited by NHS England's Information Standard. This allows the public to recognise that it is an accurate, reliable and trustworthy source of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology. Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you've already been given. Please do continue to talk to your medical team if you're worried about any medical issues. If you'd like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on 0808 800 0004 or support@thebraintumourcharity.org

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About The Brain Tumour Charity

A cure can't wait!

We are The Brain Tumour Charity and we understand that when you, or a loved one, is diagnosed with a brain tumour, a cure really can't wait.

That's why we're working faster and going further to beat brain tumours sooner.

And, as the world's leading brain tumour charity, we're the only charity to help on all three of these vital fronts:

Research

We provide essential funding o pioneering researchers, and connect people, resources and ideas to the areas where they're needed most.

Campaigning

We campaign for urgently-needed policy change, organise resource and knowledge-sharing across the world, and work tirelessly to accelerate progress towards a cure.



**WE'RE
HERE FOR YOU
AT EVERY STEP**

thebraintumourcharity.org

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