

# **Cognition and brain tumours**

'Cognition' refers to the conscious mental processes that our brain is responsible for. These include thinking, understanding, learning, attention/concentration, problem solving, planning and making decisions.

The physical presence of a tumour in the brain can affect the way your brain works, causing problems with (impairing) the functions it controls. This is known as 'cognitive impairment'.

The location of your tumour, the treatments you have and the unique way your own body works will play a part in whether, and how severely, your cognition is affected.

## In this fact sheet:

- What is 'cognitive impairment'?
- Types of cognitive impairment
- Factors affecting cognitive impairment
- Coping strategies
- Answers to some common questions you may have about cognitive difficulties

## What is cognitive impairment?

Many people diagnosed with a brain tumour will have some form of cognitive impairment, due to the presence of the tumour and the pressure it causes on the brain.

If the impairment is mild, it may not be immediately noticeable and may only come to light when you try to do more complex tasks or if you return to work. You may feel that your memory or mental functioning has "slipped". Your family and close friends may also notice a difference, but it will not generally interfere with your daily life.

If the impairment is more severe, however, it may make some aspects of daily life difficult and you may require support.

## What sort of cognitive impairment might I develop?

The following is a list of the most common cognitive effects of brain tumours. It is important to remember that not everyone with a brain tumour will have cognitive effects and that, if you do experience cognitive effects, brain tumours tend to affect some, but not all, abilities.

Various factors, such as where your tumour is located, will affect which cognitive effects you may experience, if any. (See 'What affects cognitive impairment?' section further on in this fact sheet.)

## **Attention & concentration**

You may become easily distracted and find it difficult to keep focussed on a task over a long period of time. This can include losing the thread of conversations or starting tasks and not finishing them.

Another common symptom is not being able to concentrate when more than one thing is happening e.g. when you are in a crowd, or several people are speaking at once.

The effort to overcome these can be extremely tiring as you try to focus and concentrate.

#### 'Executive functions'

'Executive functions' are the high level cognitive functions (processes of the brain) that organise and control our abilities, such as planning, organising, problem-solving, decision-making and reasoning.

Examples of things you may find difficult include:

- Going to the supermarket to get more food without being reminded (task initiation/motivation)
- Getting all the ingredients for making a meal and cooking them at the right time so they are ready at the same time (planning/organisation)
- Whilst shopping, browsing for items on a list and not picking up the first thing you see (impulse control)
- Not buying items that are tempting, as you are unable to reason that you don't need them (reasoning)
- If an item is out of stock, being able to decide what would be a suitable substitute e.g. butter instead of margarine (flexible thinking)
- Being able to remember directions or understand something that has just been explained to you (working memory)
- Putting the laundry out to dry whilst still remembering to attend to the cooking (multi-tasking)
- Controlling your emotions, leading to rapid mood changes

For some people, this can result in being fixated on one thing, having an inability to plan ahead, or make it harder to learn from previous experiences. If you have difficulties with decision making you may also make decisions that appear spontaneous or out of character.

## Thinking speed

You may feel that you are not able to think as quickly as usual, making tasks longer to complete. It can also make it more difficult to keep up with conversations.

In addition, your reaction times may be slower than usual.

## Social cognition

Social cognition refers to our ability to understand social situations and behave appropriately for the situation.

This includes knowing when to talk, when to listen and responding in an appropriate way to the views other people express.

People can lose their inhibitions, becoming inappropriately elated or depressed, over-argumentative or passive, or vulgar. They can also show little regard for the consequences of their behaviour.

If your social cognition is affected by your brain tumour, you may not be aware of inappropriate behaviour you display.

Other people may find it difficult to understand the change in your behaviour or may think you are being unreasonable. This can affect your relationships and your ability to work.

You may also have difficulties understanding humour, which can be further socially isolating.

## **Learning & memory**

Memory difficulties are usually with short-term memory, while long-term (old) memories are retained. This can mean that you may have trouble learning

new things or remembering recent things, such as recent conversations.

You may also have difficulty remembering to do things, such as keeping an appointment.

#### **Communication skills**

'Communication' refers to our ability to use and understand spoken language, body language, reading, writing and also numbers.

There are two main areas of the brain that are associated with communication: These are called 'Broca's area' (in the frontal lobe) and 'Wernicke's area' (in the temporal lobe). Any damage to these areas produces an effect known as 'aphasia'. This is the inability (or impaired ability) to understand or produce speech. It is sometimes called 'dysphasia'.

Broca's aphasia affects language production, while Wernicke's aphasia affects language understanding. In reality, the brain is not divided in to such clear cut sections, so it is possible that you may experience a combination of these two effects.

## Speech

You may make mistakes in the words you use - using the wrong word, pronouncing words incorrectly or putting words in the wrong order.

Or, if your memory cannot 'remember' words, this may make it difficult to express your thoughts.

## Comprehension

You may also have difficulty understanding words that you hear, particularly if the words are abstract, or if there is noise or other things going on to distract you.

## Reading and writing

Aphasia (dysphasia) can affect reading and writing in the same way as

speaking, so you may find you don't understand words in a book or that you write the wrong words down.

(For more information about brain tumours and communication, please see the separate fact sheet: Communication difficulties and brain tumours.)

## **Vision & perception**

Visual problems may include not noticing objects on one side. This can mean that, not only do you bump into things, but you may also be unaware of, and therefore 'forget' about, things on that side, as you cannot remember things you haven't seen.

Perception is the process of taking in information from the world, organising that information and forming an understanding or 'perception' based on it.

If you have a brain tumour, your ability to understand the world around you may be affected. Some of the difficulties you may experience could include difficulties recognising objects, judging distances, or putting things together. For example, you may not be able to recognise a pen on a cluttered desk.

Some terms you may hear in relation to brain tumours and perception are:

## **Agnosia**

'Agnosia' is a rare disorder that affects a person's ability to recognise objects, people, words and sounds. Although an individual with agnosia will see or hear something, the sight or sound is 'stripped' of its meaning. As a result, they may confuse the function of the object e.g. they may use a comb as a fork or vice versa.

## Apraxia (also known as 'dyspraxia')

'Apraxia' is a disorder of the brain and nervous system where a person has difficulty carrying out a movement or task even when they have been asked to do so and understand what they need to do.

Apraxia can make tasks, such as pouring water from a kettle, very difficult and can make the person appear clumsy.

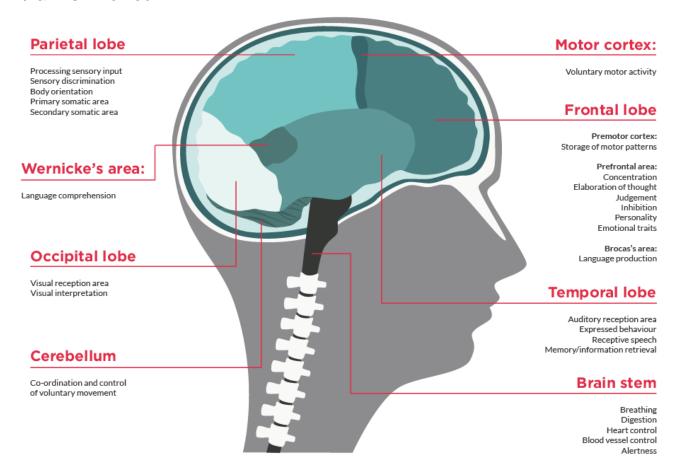
In the UK, apraxia means the complete loss of the ability to co-ordinate movements, while dyspraxia refers to partial loss of this ability. Other countries apply the terms in various ways.

## What affects cognitive impairment?

There are various factors which will affect whether you are likely to experience cognitive impairment and what type of impairment you might have.

#### Location of tumour in the brain

Each section of the brain (*see diagram below*) is responsible for different functions, some of which are quite complex and wide-ranging. As a result, the likelihood and degree of cognitive impairment you may experience, will be affected by the location of the tumour and how many functions that area of the brain is involved in.



Below is a list of the cognitive functions that are likely to be affected according to the area of the brain that your tumour is located in.

It is important to remember that this list is not definitive and that tumours in one lobe/area can cause difficulties with cognitive functions that are listed under another lobe/area.

#### Frontal lobe

- attention & concentration
- executive functions \*
   e.g. planning & organising, decision-making, problem-solving
- thinking speed
- communication skills, language production
- social cognition, impulse control and sexual behaviour
- emotional control
- memory
- (\* Executive functions may involve the various lobes of the brain, but they are generally co-ordinated in the frontal lobe, which acts like the conductor of an orchestra.)

## Temporal lobe

- memory
- communication skills, understanding language
- speech
- hearing

#### Parietal lobe

- perception
- spatial relationships
  - e.g. recognising body position, understanding left/right, up/down \*
- recognising faces/objects
- communication skills

(\* Not being able to recognise up/down, left/right makes it difficult to add or multiply numbers or read information in columns)

## Occipital lobe

- vision
  - e.g. locating objects and identifying their movement

#### Cerebellum

- co-ordination
- executive functions
- attention

#### Brain stem

- alertness, awareness
- co-ordination
- controlling muscles involved in speaking, swallowing

## Left and right hemispheres

The brain is divided into two hemispheres - left and right. The side on which your tumour is located can also affect the type and likelihood of cognitive effects. For example, if your tumour is located on the left hemisphere, you are more likely to experience cognitive impairment relating to language and speech.

#### **Treatments received**

Surgery, radiotherapy and chemotherapy can all interfere with your memory and your thinking/reasoning skills, at least temporarily.

## **Surgery**

As with any invasive procedure, surgery on the brain can produce many sideeffects. Firstly, to get to the tumour, the surgeon has to go through normal brain tissue, which may cause some damage to that tissue.

Secondly, as a response to the 'trauma' of surgery, the body's normal reaction is to produce swelling. This is designed to protect or cushion tissue. However, in the enclosed space of the skull this swelling causes increased pressure on the brain and so affects how that part of the brain works, causing possible cognitive effects.

Most of these effects are temporary until the brain recovers from the surgery and the swelling reduces. Steroids may be given to help with this. (For more information, please see the Neurosurgery for brain tumours and the Steroids fact sheets.)

In some cases, the surgery, due to the removal of the mass of the tumour and the pressure it was causing on the brain, can lead to an improvement in aspects of cognition e.g. word fluency, verbal memory and visuospatial memory. (This is the ability to recognise visual objects and their relationship in space, and is needed for tasks, such as finding your way around a room without bumping into things or round a familiar city, or doing a jigsaw puzzle.)

However, the purpose of the surgery is to remove as much of the tumour as possible. The removal of this brain tissue, by its very nature, can lead to cognitive impairment, affecting whichever function that the particular part of the brain is involved in.

## Radiotherapy

Unfortunately radiotherapy to the brain can increase the risk of developing cognitive impairment, but this may not appear until months or even years after treatment. It can also get worse over time.

This is due to the radiotherapy causing disruption to the blood-brain barrier and damage to the blood supply to the brain cells in the treated area. Initially this can lead to retention of fluid (oedema/swelling) which presses on the brain cells causing damage. You may hear this referred to as 'radiation induced encephalopathy'.

The damage to the blood supply can also lead to a shortage of oxygen and nutrients to the brain cells, which over time, can eventually cause the cells to die. You may hear this referred to as 'radionecrosis'. As a result, the functions of that area of the brain are affected. This can cause physical as well as cognitive effects.

People who have undergone radiotherapy using higher doses of radiation at each 'fraction' (treatment session) have been found to be more at risk of these long-term cognitive effects. However, in the UK (and the USA and Europe), the general standard of treatment is usually at a level per fraction to try and prevent this. Occasionally, however, people may be given a higher dosage for palliative treatment i.e. to improve their quality of life.

## **Chemotherapy ('chemo brain')**

People being treated for various types of tumour, not just brain tumours, report problems particularly with memory and concentration after having chemotherapy. This is often referred to as 'chemo brain' or 'chemo fog'. The changes in cognitive function are usually mild, but they can affect your quality of life.

It is not clear what causes this chemo brain and some people say that this term is misleading, as similar effects have been reported in people who have not had chemotherapy. Chemo brain, therefore, could be a result of the treatment itself, of emotions such as anxiety, other factors such as fatigue, or a mixture of these.

#### **Medications**

#### **Steroids**

You may have been prescribed steroids to help with some of the symptoms of your brain tumour, such as swelling after surgery, headaches or if you are experiencing nausea after chemotherapy or radiotherapy. (*Please see Steroids fact sheet for more information.*)

Side-effects with steroids are common, often causing mood disturbances, problems with attention/concentration and memory impairment.

You may feel anxious, irritable and experience mood swings. A small number of people, if given high doses while in hospital, may also experience 'steroid-induced psychosis'. This can include periods of 'hypermania' alternating with periods of depression. During the hypermania phases you may become prone to making impulsive and rash decisions.

These effects are usually temporary whilst taking the steroid, but if you experience any of these symptoms, please discuss it with your health team <u>immediately</u>.

Steroids, however, can improve cognitive deficits (problems) by reducing swelling or retention of fluid (oedema) and thereby reducing the pressure on the brain.

## **AEDs (Anti-Epileptic Drugs)**

Around 60% of people with a brain tumour will experience a seizure at least once and people with low grade tumours are more likely to experience seizures (epilepsy). As a result, many people with brain tumours will take AEDs.

Some older AEDs have been known to cause such cognitive side-effects. Newer generation AEDs are less likely to cause cognitive effects, and have fewer effects when they do.

Depending on the AED you are taking, you may experience cognitive effects, such as impaired memory, impaired attention and effects on executive functioning, such as slowness in thinking.

If you experience any cognitive side-effects, discuss them with your health team, as there are other drugs they can swap you to.

#### Over the counter medicines

Some over-the-counter medicines can affect cognitive functioning. Talk to your health team about any possible side-effects.

## **Epilepsy**

As well as the AEDs, the seizures themselves are thought to have an effect on cognitive functioning. People with epilepsy seek help for memory problems more often than for any other impairment, possibly because of the high frequency of the temporal lobe being involved.

Some studies have found that having seizures on top of a brain tumour and brain tumour treatment, can impair a wider range of cognitive functions, even more than radiotherapy.

People with brain tumours and epilepsy have been found to have slower processing speeds and problems with attention and executive functioning.

## **Fatigue**

One of the most common side-effects of dealing with a brain tumour is fatigue. This can be due to a variety of causes - the impact of the tumour itself, your treatments or medications, if you have seizures, plus the stress and anxiety caused by the diagnosis and future uncertainty.

Fatigue is well-known to cause cognitive impairment, particularly with memory, attention/concentration and planning and organising, as it can deplete the energy required for these functions. (For more information, please see our Fatigue and brain tumours fact sheet.)

## **Emotional/psychological factors**

A brain tumour diagnosis, and everything it brings with it, is such a huge life event that it is common for people to feel anxious, depressed and fearful of the uncertainty. Changes in your personal, social and/or professional life as a result of the tumour- dependency on care givers, loss of self-confidence and unemployment - can add to these feelings. These reactions and associated mood changes frequently negatively affect cognitive functions such as attention/concentration, memory and motivation.

## Other factors

#### **Diet**

Eating well can combat fatigue, make you feel better and make your body more able to cope with the side-effects of treatment. So if you are not eating well, possibly as a result of your treatment, you may find that the cognitive effects you are experiencing are worsened.

Try to eat well, although often through the effects of the treatment or the brain tumour itself, you do not feel like eating. In this instance, it is important that you do eat, so eat a little of what you like rather than nothing. (*For more information, please see our Diet fact sheet.*)

#### **Alcohol**

The effects of alcohol on the brain are well-known - a general 'depressive' effect on brain activity, leading to slowness of thinking and reaction times, impaired reasoning and memory problems.

## **Summary**

It is important to realise that you are very unlikely to experience all these cognitive effects. The combination of tumour location, epilepsy, surgery, radiotherapy, AEDs, steroids, and psychological distress, along with your fatigue levels and general health, are all likely to contribute to cognitive impairment in an individually unpredictable way. Your experience is personal and likely to be different from another person affected.

It is important to remember that while some of the cognitive effects you experience may be long-term, others will be temporary or may be able to be lessened by 'cognitive rehabilitation' therapies.

# Are there any treatments available for cognitive impairment?

While there is no simple 'cure' for cognitive impairment, your health 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 are 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 is less likely to add to your 'cognitive burden'.

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

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

## What can I do to cope with cognitive difficulties?

Cognitive impairment, such as 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 is not unusual to feel frustrated, defensive and embarrassed about the changes in some of your abilities.

Speak to your health team if you have such concerns as they will be familiar with your specific diagnosis and circumstances. 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. Below are some suggestions that you may find useful depending on what sort of cognitive impairments you are experiencing and how severely they are impacting your daily life.

## **General coping strategies**

#### 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 are 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 are doing as you go along to keep track of where you are.

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

#### Making 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 have fully understood.

To make it easier to concentrate, try to remove background noise, for example, switch 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 have made in order to remember information.

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

Use other memory aids, such as alarms, diaries, mobile phones etc. Some people find it useful to use photos of tasks or stages 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 will be easier to remember.

#### Talk to others

Talking to those close to you about how you are feeling and the difficulties you are 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 other people know when you are having difficulties, for example, when talking to them - 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.

- Aid concentration by pacing yourself and reducing distractions
- Try to achieve a regular sleep pattern
- Reduce alcohol intake
- Try to manage your stress.

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

## How are cognitive difficulties 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 are having, you will 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 is important to know that most people do not complete all the tasks.

Information is often also collected from friends and family as, if you have cognitive impairments, you may be unaware of the difficulties, or extent of difficulties, you have.

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 will be invited back for a feedback appointment to discuss the results and look at relevant coping strategies.

## What if I have further questions?

If you require further information, any clarification of information, or wish to discuss any concerns, please contact our Support and Information Team:

- Call: 0808 800 0004
   (Free from landlines and most mobiles:
   3, O2, EE, Virgin and Vodafone)
- Email: support@thebraintumourcharity.org
- Join our closed Facebook groups:

bit.ly/facebooksupportgroup

bit.ly/carersupportgroup

## **About us**

The Brain Tumour Charity makes every effort to ensure that we provide accurate, up-to-date and unbiased facts about brain tumours. We hope that these will add to the medical advice you have already been given. Please do continue to talk to your health team if you are worried about any medical issues.

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research to increase survival, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We rely 100% on charitable donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us including fundraising, leaving a gift in your will or giving in memory, please visit us at thebraintumourcharity.org, call us on 01252 749043 or email fundraising@thebraintumourcharity.org

## About this fact sheet

This fact sheet has been written and edited by The Brain Tumour Charity's Support and Information Team. The accuracy of medical information has been verified by a leading healthcare professionals specialising in neuropsychology. Our fact sheets have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence. If you would like a list of references for any of the fact sheets, or would like more information about how we produce them, please contact us.

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Your notes





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