

Coping with speech and language difficulties

Living with a brain tumour



It's important to remember that if you have speech and/or language difficulties, you:

- Are still an intelligent person
- Know what you want to say
- Can still make your own decisions.



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:

thebraintumourcharity.org/facebook-support

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Introduction

Being able to speak and understand what is being said to us is essential to communication. It allows us to express ourselves, to understand others and plays a large part in being independent in our personal and professional lives.

Brain tumours and their treatment, if they affect the parts of the brain involved in speech and language, can interfere with this.

Not everyone who has a brain tumour will experience speech and language difficulties, but when they occur, they can make you feel frustrated, angry, embarrassed and isolated from the people around you.

Here are some tips for dealing with speech and language difficulties from people affected by a brain tumour and from healthcare professionals specialised in treating brain tumours.

They may help you, and those around you, to feel more in control and so reduce these feelings.

What are speech and language difficulties?

Speech and language are different. An individual can have difficulties with either speech or language or both.

Sometimes these terms can get confused, and you may think you have a speech problem, when actually it's your language that has been affected.

Speech is the physical ability to produce individual sounds and words. Speech is how we use our tongue, lips, jaw muscles and vocal tract to produce sounds.

So speech difficulties mean you find it physically difficult to speak. This can be due to the brain tumour affecting the control or co-ordination of the muscles involved in speaking.

Language is the words we use and how we use them to communicate meaning, e.g. how we put words together or what words mean. Language can be written or spoken.

So language difficulties (known as aphasia) mean you find it cognitively (mentally) difficult to:

- produce language (speak)
- understand language (comprehension)
- read and/or write.

What might help with speech and language difficulties?

Here are some simple tips that may help you, your family and friends:

For the person experiencing speech and language difficulties

- Try to create a relaxed environment - aphasia often worsens with stress
- Reduce background noise and distractions e.g. turn off the radio/TV when talking to someone
- Consider taking a break if you're tired
- Slow down when trying to talk
 - this can help you with your speech and also help others to understand you.
- Don't forget the importance of breath support! Make sure you take a good deep breath before speaking
- Try leaving a space between each word
- Try to keep your sentences short, especially if you're feeling tired
- Never feel worried to repeat yourself!
- Keep a notepad handy to write down important information. You can also put up a noticeboard, calendar or keep post it notes in a visible place with reminders on them. Or you can use your phone.

For family and friends

Communication is a two way process. As such, the way that family and friends communicate with the person who has speech or language difficulties, is also very important.

One of the key ways you can help is to be supportive and to adapt the way you communicate to help your loved one understand and express themselves.

Here are a few tips for family and friends that people said have helped:

- Always face the person when you're having a conversation
- Reduce any distractions or background noise
- Don't rush your speech - speak clearly and at a steady pace
- Give one point at a time, rather than all of the information at once, and don't suddenly change subject
- Use short sentences
- Use all forms of communication, including mime, gesture, intonation, writing, drawing, and facial expressions. There are also communication boards and other aids that can help.

*(Please see the **Resources** section of this fact sheet on page 14 for more information.)*

- Write down key words
- If the person hasn't understood you, try rephrasing what you've said - don't just repeat the same sentence over and over again
- Make giving answers easy. Questions that need a yes/no response are easiest. For example, instead of asking "Would you like tea or coffee?", you could ask, "Would you like tea?"
- Don't be tempted to speak more loudly - remember that the person doesn't have a hearing problem .
- Take care not to talk down to the person with the communication difficulty - the problem isn't with their intelligence.
- Be patient. Give the person plenty of time to respond.
- Be open and honest. Don't pretend to understand what the person has said if you don't. This will probably be obvious to the person and may frustrate them.
- Don't interrupt, fill in words or finish a sentence for a person unless they ask you to - it can be really frustrating for the person who is trying to talk to you.
- If the person is having difficulty with a particular word, you could ask them to describe it instead.
- Relax and be natural

- Reduce background noise
- Recap - to check that you both understand
- Consider taking frequent breaks. The person will find communication more difficult and tiring than before. It can also be tiring for you
- Ask them what helps.

Many carers have found that it's important not to do too much for their loved one just because it's easier, and to remember that the person with aphasia:

- Is still an intelligent person
- Knows what they want to say
- Can still make their own decisions.



Help for family & friends

Family and friends often report feeling lonely and isolated too. They can feel emotions, such as helplessness or guilt, watching their loved one struggle to communicate. Their relationship may also have changed.

For this reason, it's important that family and friends, caring for someone with a brain tumour, look after themselves too. It's well-known, but often forgotten, that you can only care well if you care for yourself. And it can be easy as a 'carer' to forget that you deserve to be taken care of too.

While it's important you're in good health (mental and physical) so you can care for your loved one, it's also important you remember to take care of yourself for you too.

Being a carer is a selfless and difficult thing to do, and likely not something you ever expected or wished to be doing. So be kind to yourself and remember to take a short break, a day away from it all or take time to share with a loved one.

For more information and tips on coping, see our **Carers - looking after yourself** webpage and fact sheet: thebraintumourcharity.org/being-a-carer

What healthcare interventions are available to help with language problems?

Language problems (known as aphasia) are commonly caused by a one-off event (for example, a stroke or a head injury) and, in these circumstances, some degree of natural recovery is usual.

When a brain tumour is the cause, however, aphasia may get worse if a tumour grows.

You may have been referred to a speech and language therapist (SLT) following surgery for your tumour.

See our webpage and fact sheet on the **Multidisciplinary Team [MDT]: thebraintumourcharity.org/your-mdt**

To offer the best help, the SLT first gives you a variety of spoken and written tests, such as naming objects, engaging in conversation, telling a story or joke, or writing a shopping list.

These are used to assess which sort of communication difficulties you're having and to what degree.

They'll then work with you, using various tools and exercises, towards three key goals:

- Relearning lost or damaged communication skills (if possible)
- Making the best use of remaining communication skills
- Finding new ways of communicating.

If you've not been referred to an SLT, or you've not had surgery, but are interested in finding an SLT, there are a variety of ways you can do this.

Finding a speech and language therapist (SLT)

Get an NHS referral

Speak with your healthcare team. This could be your consultant, clinical nurse specialist (CNS), key worker or GP. If you explain that you think you would benefit from seeing an SLT, they should be able to make a referral to your local team for you.

Keep in mind that there can often be a little bit of a wait for a referral, so make sure you have these conversations as soon as possible.

Refer yourself

You can also refer yourself to your local Speech and Language Therapy Department. To do this, contact your local NHS service or GP and ask for the contact details of the local NHS Speech and Language Therapy Service. You can then get in touch with them directly.

Go private

Some people consider seeing a private or independent speech and language therapist. If this is something you're interested in, the **Association of Speech and Language Therapists in Independent Practice (ASLTIP)** can help you find the right therapist for you.

They have a database of therapists on their website, which allows you to search in your local area for specific, independent speech and language therapists. You can filter your search based on your age, what type of therapy or support you're looking for and how far you're willing to travel.

When looking for the right speech and language therapist for you, we recommend you search for therapists who work with adults with acquired brain injury (including stroke), as this is likely to include brain tumours.

You can also look on the Royal College of Speech and Language Therapists website. They have lots of information about different types of speech and language therapy and how you can find therapists.

Resources

While The Brain Tumour Charity cannot recommend any specific organisations, the following organisations provide support with speech and language difficulties:

- **Stroke Association** - Provides information and communication tools
stroke.org.uk/what-is-aphasia/communication-tools 0303 3033 100
- **Brain and Spine Foundation** - Provides information and support on neurological disorders for patients, carers and health professionals
brainandspine.org.uk 0808 808 1000
- **The Royal College of Speech and Language Therapists**
Offer speech and language therapy services
rcslt.org For general information and professional enquiries - Tel: 020 7378 3012; Email: info@rcslt.org
- **National Aphasia Association (USA)** - Suggests using word games like Scrabble or crosswords to re-inforce any speech therapy a person is doing and to keep the mind active.
aphasia.org/stories/word-games-aphasia
- **Amy Speech & Language Therapy, Inc.** - Has sets of free, downloadable communication boards for adults and children on a range of different topics.
amyspeechlanguagetherapy.com/communication-boards.html

- **The Tavistock Trust for Aphasia** - A website that has information about apps and software programs to help people with aphasia .
aphasiasoftwarefinder.org
- **JAM cards** - allow people with a communication barrier, learning difficulty or autism tell others they need 'Just A Minute' discreetly and easily.
jamcard.org



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About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard - an NHS standard that allows the public to identify reliable and trustworthy sources 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

Going further for a cure

As the UK's leading brain tumour charity, we're here to accelerate a positive change in how people affected by brain tumours are diagnosed, supported and cured.

Brain tumours strike fast. And they can strike anyone, at any age. But what if we could move faster? What if we could stop brain tumours right in their tracks? It's no easy task taking on something this complex, but that's exactly what we're here to achieve. And we won't stop until we have.

We know that if we put our heads together, we're more than up to the challenge. So we're building a movement of people from every walk of life – all coming together to accelerate a cure.

Find out more and get involved:
thebraintumourcharity.org



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

thebraintumourcharity.org

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