

Cognitive Communication Disorders – public information

DRAFT FOR CONSULTATION

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The information in this document is currently in development and has been shared as part of a consultation. If you are seeking guidance or information on this topic, please ensure you refer to final published content which can be found on rcslt.org.

We appreciate any comments provided to us during the consultation, all of which will be reviewed by the working group within the context and scope of the project. We ask that, where possible and relevant, you accompany any counter arguments to statements made in the document with supporting evidence e.g. a research reference.

Members of the working group should not be contacted directly, and all feedback should be made through the assigned route e.g. via survey or project manager. Feedback made through unassigned routes or after the closing date will not be accepted or responded to.

Thank you for your support with this project.

Cognitive Communication Disorders – public information

The following information is aimed at people with cognitive communication disorders, their families, friends, and carers, and professionals.

A summary of the information is available as a downloadable factsheet in the resources section,

Specific information for professionals can be found as downloadable factsheets in the resources section.

1. What are cognitive communication disorders?

Communication is a complex process. We have to work out what, when, and how we should communicate and how others may interpret it. This requires us to understand what other people are saying, what we and others are thinking, and what the situation requires us to say (or not say). We use our 'cognitive' skills, such as attention, memory and problem-solving, to do this. We also use a set of skills known as 'executive functions' that allow us to monitor and co-ordinate our behaviour.

Brain injury and neurological conditions can affect our cognitive skills, which in turn can affect all aspects of communication including listening, understanding, speaking, reading, writing, and conversation. The term 'cognitive communication disorders' is used to describe these communication changes.

2. What are the signs of cognitive communication disorders?

There is great diversity in communication styles across different people, cultures, and languages. However, changes to a person's individual communication style due to brain injury or a neurological condition are common.

Every person with a cognitive communication disorder is different, but symptoms may include:

- difficulty concentrating during conversations
- forgetting what they or others have said
- difficulty processing what they have heard or read
- difficulty thinking of things to say or write
- difficulty finding the right word to say
- difficulty speaking, understanding, reading, and writing when there are distractions such

- as background noise or movement
- missing out important information when speaking or writing
 - difficulty putting their thoughts into words in a logical order
 - saying too much or too little without realising
 - making comments they would not normally say
 - going off on a tangent
 - repeatedly talking about the same topic
 - needing extra time to respond
 - acting overly friendly, affectionate, blunt or rude
 - facial expressions not matching what they are saying or thinking
 - difficulty recognising emotions in themselves and others
 - difficulty seeing things from someone else's point of view
 - missing social cues that indicate sarcasm, humour, etc.

Other people may be able to see these difficulties more than the person with a cognitive communication disorder. This is because people with cognitive communication disorders may have little or no awareness of the changes.

A person's communication skills may change and get worse at different times of the day, with different people, and in different situations. This can be due to fatigue, anxiety, pressure, or feeling overloaded.

Cognitive communication disorders can occur at the same time as other communication difficulties such as unclear speech or aphasia. However, they are not the same as being neurodivergent or dyslexic, although a person with a cognitive communication disorder may also be living with these. These issues can make cognitive communication disorders harder to detect.

3. What problems can cognitive communication disorders cause?

Communication is important to all aspects of life. Nearly everything we do at home, in the community, and at school or work requires spoken or written communication in some way.

If communication becomes harder due to a cognitive communication disorder, there can be a devastating impact for the person, their family, friends, and carers. It could affect any part of family, social, school, and work life.

Common problems include:

- difficulty forming and maintaining relationships with family, friends, peers, carers or colleagues
- difficulties in work, such as following meetings, understanding and writing emails, delivering presentations, or reading and writing reports
- difficulties in school, college or university such as understanding classes, answering questions, or writing coursework and taking exams
- difficulty with leisure activities including watching films, reading books, or using social

media

- difficulty with tasks such as filling out forms and learning new processes
- avoiding social events as it is hard to follow group conversations, answer people's questions, or think of things to say
- greater role of everyday communication partners in following and supporting interactions with a person with cognitive communication disorder.

Children and young people with cognitive communication disorders face additional challenges, as communication skills that were still developing when the injury happened, may be more severely affected as a result. Their cognitive communication disorders can evolve or emerge over time, as cognitive processes fail to mature as expected. The impact can worsen over time as children fall away from the expected developmental trajectory. This delayed onset and impact can make it difficult to relate current difficulties to a past brain injury.

For all, such changes can affect the following in both the person with cognitive communication disorder and their families:

- sense of self
- social contact
- confidence
- quality of life
- educational attainment
- employment status
- independence.

People with cognitive communication disorders, and their family members, can end up feeling sad, isolated, frustrated or worried.

4. Causes

Cognitive communication disorders can be hard to detect so it is difficult to be certain about the number of people affected. However, research suggests that cognitive communication disorders are experienced by significant numbers of people with a traumatic brain injury (MacDonald, 2017), people who have had a stroke (Hewetson et al, 2017), people with Parkinson's disease (Swales et al., 2020), people with multiple sclerosis (Carotenuto et al, 2018). It is also known that people with other neurological conditions, such as motor neurone disease (Fisher et al, 2017), dementia (Harciarek & Cosentino, 2013), and Long COVID (Cummings, 2023) can experience cognitive communication disorders.

5. What can people with a cognitive communication disorder do to help their communication?

Everyone with a cognitive communication disorder will have different needs and symptoms. Different strategies will help different people. Some suggestions for strategies follow.

Preparation and planning

- When meeting family and friends, prepare things you want to tell them and questions you want to ask.
- It may help to make a note of the things you want to say and the questions you want to ask.
- Try to have conversations in quiet and calm space.
- Where possible, consider keeping groups to a small number of people.
- Prepare for the impact of fatigue, eg by resting before important conversations and plan how to take breaks.

Speaking clearly and concisely

- Take your time when talking.
- Stop, think and check before speaking.
- Ask for a minute to gather your thoughts if you need to.
- If you cannot think of the word you need, try to think of a different word or describe it.
- Try to be concise and relevant.

Staying on track

- Try to stay focussed on the current conversation topic.
- Check that people are following what you are saying.
- Let people know if you've lost track of the conversation.
- Ask people to repeat information or write it down.
- Make notes on your phone, tablet or laptop or take a photo.
- Try to monitor other people's facial expression and body language. If they look like they want to say something, invite them to do so.

6. How can others help a person with a cognitive communication disorder?

The key principles are:

- people with a cognitive communication disorder will have different support needs
- there is a balancing act between being supportive and being respectful
- do not assume you know what the person wants to say or that you know how to help
- be patient and keep listening
- ask the person how best to support them eg holding up a hand if they are dominating the conversation and not turn-taking
- do not exclude them or make them feel different
- if they become defensive, reassure them with respectful and kind words
- follow any strategies that have been provided
- ensure the environment is quiet and calm.

You can help when **you are speaking** by:

- taking your time
- talking at a speed which allows the person to follow what you are saying

- explaining yourself clearly and in concrete terms that the person is familiar with
- talking in shorter sentences to make it easier for the person to process what you've said
- allowing time and silence to enable the person to consider what you are saying
- checking back that you have been clear and are understood
- reading aloud complex written information
- giving written or visual versions of information that the person can take with them
- remembering that these communication changes are due to their neurological changes, not their personality
- allowing the conversations to be revisited once the person has had time to process the conversation and think of what they want to say.

You can help when the **person with a cognitive communication disorder is speaking** by:

- ensuring time and silence to give the person time to gather their thoughts
- finding the right time and place to ask for clarification or to offer help if they seem stuck
- recount stories and events together, ie you tell a bit, they tell a bit
- double checking if you think they've used the wrong word
- gently highlight if they've gone off topic
- checking back that you have understood
- be aware that open questions are harder to answer
- be prepared to ask closed questions or give options
- you may need to dictate notes for their compensatory memory aid (phone, laptop or computer) or remind them to take a photo of an event.

7. How can speech and language therapy help?

Speech and language therapists have the specialist knowledge and skills to support communication difficulties, including cognitive communication disorders.

Speech and language therapists can:

- work with the person, family, and professional teams to assess and identify how communication has changed and the impact it has on their daily lives
- support people with cognitive communications disorders, their family and friends, and the professionals working with them to understand the condition, its impact, and how to help
- support the person, family and professional teams to identity what they want to achieve (their goals)
- collaborate with the person, family and professional teams to provide the best possible treatment and strategies to help the person achieve their goals and improve family, social, school or work life
- support people with cognitive communication disorders to participate in decision-making about their lives, rehabilitation, and care
- provide communication partner training to families, friends, and professionals
- help people with cognitive communication disorders, and their family and friends, regain confidence, self-identity, and quality of life.

8. How and when to refer to speech and language therapy

GPs, healthcare professionals, social worker or teachers can make a referral to speech and language therapy.

If the person has worked with speech and language therapy in the community before, they may be able to make a re-referral themselves.

Referrals and re-referrals can be made at any time in the person's journey if they have communication problems that they would like help with. This can include new or increased problems that are noticed further down the line or when life changes.

9. Resources

The following resources may be useful:

RCSLT downloadable factsheets on:

- cognitive communication disorders for people with cognitive communication disorders, their families, and friends
- cognitive communication disorders for professionals

The following organisations also offer information on cognitive communication disorders in different conditions:

- **Headway** (a charity for people with brain injury) offering information on cognitive communication disorders
Headway can also provide an [individualised brain injury information card](#) (brain injury will require verification from a professional)
- **MND association** (a charity for people with motor neurone disease) provide information on how changes to thinking and behaviour can impact communication in their [guide on changes to thinking and behaviour with MND](#)
- **MS Society UK** (a charity for people with multiple sclerosis) supply information on [speech and communication problems in multiple sclerosis](#)
- **Parkinson's UK** (a charity for people with Parkinson's disease) share information on [speech and communication problems in Parkinson's disease](#)
- **Stroke Association** (a charity for people who have experienced a stroke) have downloadable leaflet on [communication problems after stroke](#)
- **The Children's Trust** (a charity for children with brain injury) provide information on [speech, communication, and talking with children with an acquired brain injury](#)

10. References

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