Coping with communication problems after brain injury

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the brain injury association

Headwa

This booklet describes the many forms of speech, language and communication problems caused by brain injury. Practical strategies are provided for people with a brain injury, their families, carers and friends who are trying to cope with these difficulties. This booklet is an adaptation, created in May 2016, of the Headway print booklet *Coping with communication problems after brain injury* and may contain minor updates to the original version.

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Introduction

Communication problems after brain injury are very common. Although most of us take it for granted, the ability to communicate requires extremely complex skills and many different parts of the brain are involved.

There are four main categories of the effects of brain injury. Any of these can cause communication problems:

- Physical affecting how the body works
- Cognitive affecting how the person thinks, learns and remembers
- Emotional and behavioural affecting how the person feels and acts

Many people will experience more than one form of communication problem after brain injury, depending on the areas of the brain affected and the severity of the injury. It is also important to recognise that such problems may occur alongside other changes in physical, cognitive, emotional and behavioural functions.

The diagram below shows the cerebral cortex. The cortex is the outer part of the brain, which is responsible for our more sophisticated thinking skills. Many of the functions listed are important for communication, and injury to any of these areas can impair communication skills.



Any communication difficulty has the potential to affect the person's everyday life and the lives of those around them. The problems can lead to reduced social contact and impaired ability to live independently and carry out previous activities (e.g. working and caring for family).

Support, rehabilitation and awareness can reduce these effects and the information in this booklet should help you to increase your understanding of the difficulties.

In order to understand how brain injury affects communication skills, it is important to know about how communication works. The next section deals with this subject.

What is communication?

Successful communication involves exchanging information between two or more people by speaking, writing, or using some other medium. This involves two key aspects: verbal communication and non-verbal communication.

While we tend to be aware of our verbal communication, much of non-verbal communication is sub-conscious and automatic. Both aspects can be just as important for conveying information, either deliberately or unconsciously. Verbal and non-verbal skills are both involved in another key aspect of communication: social communication.

As these skills come so naturally to most people, it is only when they are impaired that we realise how important they are. Different combinations of physical, cognitive, emotional and behavioural effects of brain injury can affect verbal, non-verbal and social communication skills. Each of the long-term communication difficulties outlined later in this booklet can reflect problems in any of these areas.

This section will now describe the three aspects of communication in more detail.

Living with communication problems

You just don't appreciate how amazing language is until you've lost it. It's incredible when you think about it, the way we can transfer thoughts from one mind to another using words.

Verbal communication

Verbal communication includes both spoken and written language. It requires an ability to understand and use words and sentences effectively.

Words are 'symbols' that represent things in the real world. Some words name things, e.g. objects (hat) or people (Jane). Other words represent abstract ideas, such as emotions (happiness). We learn words throughout life, from infancy onwards. By adulthood, each person will know and be able to use many thousands of different words correctly and without consciously thinking about it.

Words string together into sentences which are structured according to grammatical rules. The structure of sentences can be simple, such as 'the dog ate its dinner'. It can also convey complex ideas, such as 'the player who wore the number 7 shirt failed to score from the penalty spot'. Children rapidly acquire the ability to construct sentences and adults are generally able to understand and use sentences of variable complexity.

Verbal communication involves a wide range of skills, such as:

- Being able to express thoughts through spoken or written language
- Understanding words and sentences used by others
- Being able to select the correct words
- Being able to say words clearly
- Speaking at the right speed (not too slow or fast)

- Being able to vary intonation within speech (e.g. pitching speech differently when making a statement or asking a question)
- Being able to vary the volume of the voice (e.g. to speak loudly, quietly or to whisper)
- Being able to put words into logical sentences
- Using tone of voice to indicate anger, humour or sarcasm

Non-verbal communication

The way we stand, sit, move, gesture and use facial expressions gives others a lot of information about what we mean and how we feel. Sometimes the information we give non-verbally can be more powerful than the accompanying verbal communication.

Our ability to 'read' non-verbal messages often depends on the culture we live in. When we travel abroad, we may occasionally 'misread' signals and unintentionally give inappropriate messages. For example, a 'thumbs up' sign may have different meanings in different cultures. Different cultures also vary in the amount of physical contact and proximity used when communicating.

Non-verbal communication includes a wide range of factors, such as:

- Body language folded arms and foot tapping may come across as impatience or irritation
- Proximity standing too close can come across as aggressive or an invasion of personal space

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- Facial expression smiling may indicate friendliness while frowning may suggest disapproval
- Eye contact absence of eye-contact can come across as disinterest while overly intense eye contact can seem aggressive

Social communication

Social communication relies on an awareness of the feelings and intentions of other people, and of how to interact with them. This includes both verbal and non-verbal skills. As with other forms of communication, there may be culture-specific variations as to what social behaviour is acceptable.

Social communication skills include:

- Being able to monitor and control the amount of output for example, giving adequate information without talking too much and 'hogging' the conversation
- Being able to maintain a shared topic
- Being able to move on from one topic of conversation to another
- Using an appropriate manner and style of interaction (e.g. being polite and respectful to others)
- Being able to understand and use 'figures of speech' (e.g. 'the right hand doesn't know what the left hand is doing')
- Being able to understand, respond to and use humour and sarcasm effectively

Communication is reliant upon successful understanding and use of the verbal and non-verbal skills described above. Brain injury can affect these skills in different ways at different stages of recovery. The following sections explain the most common difficulties in the early stages after injury, before going on to describe the potential long-term problems and how to cope with them.

Living with communication problems

It's like having a malfunction with the start/stop buttons. Sometimes, when you try to communicate you get stuck on pause. The words are there but the message just doesn't get through to tell the mouth to start speaking.

Communication in the early stages of recovery

Coma

When first injured, the person with the brain injury may be unconscious and/or sedated to aid their recovery. During this period, they will show little or no response to speech. It may be unclear how much awareness your relative has when they are in a coma and there are no definitive approaches to communicating with them.

It is common for family members to feel quite powerless, but the hospital staff may be able to advise on ways that you can help. Some people believe that stimulation activities can be useful and you may want to refer to the Headway factsheet *Coma stimulation – suggested activities.* It is very important to discuss any activities with the staff first. Some tips for basic communication are also included below.

The person may require a wide range of medical management. This may include insertion of a tracheostomy tube to aid breathing. The tube goes below the level of the voice box, which means that, even if conscious, the person will not be able to make audible speech. If the tracheostomy needs to remain in place for a longer period when the person has come out of a coma, the medical team may suggest the use of a special valve. This redirects air through the voice box, so that the person can speak through it.

Tips:

- Talk for short periods about things of interest to the person
- Keep communication clear and simple and speak in the way you normally would
- Use different kinds of communication such as playing taped messages or their favourite music (this needs to be cleared with staff and may not be possible in shared rooms)
- Use varied types of interaction, following guidance from staff, e.g. touch, music and reading
- Try not to bombard the person with information, loud music or bright lights in an attempt to stimulate them
- Avoid having too many visitors around the bed area at the same time
- Introduce visitors by name and allow them to say hello one at a time
- Aim for only one person speaking at any one time

You can find further information on this subject in the Headway factsheet *Coma and reduced awareness states*.

Post-traumatic amnesia

As the person recovers, they may have a period of appearing agitated, confused and unsure of where they are. This stage is called post-traumatic amnesia (PTA) and passes in time. The length of PTA depends on the severity of the injury and can last from a few hours to several weeks.



The person may still be uncommunicative at this stage, or may produce quite confused speech. This may include information that, although plausible, is not correct. For example, the person may believe they are at work or going to an appointment. This is called confabulation and is not lying but the result of the brain attempting to fill in the information missing from memory.

People's behaviour can be very difficult to manage when in PTA and can be disinhibited, aggressive and embarrassing. This can be very distressing for relatives.

Tips:

- Try to stay calm because seeing other people distressed could add to the person's agitation and confusion
- Don't overload the person with information as they are unlikely to remember it and it can just add to their confusion
- Keep visitors to a minimum having a rota may help
- Watch out for signs of fatigue, such as increased agitation or loss of focus, and allow a rest period
- When changing topic, pause and give time for the person to make this change with you
- Do not push the person to respond
- If unsure whether the person has given accurate information, check with the relevant staff for clarification - try to give accurate feedback, but avoid arguments at this stage
- If they persist with inaccurate information it is best not to correct them as this may only add to their agitation
- Try not to take aggressive, abusive or embarrassing behaviour personally – people have little control of their behaviour at this time and will probably have no memory of it afterwards

You can find further information on this subject in the Headway factsheet *Post-traumatic amnesia*.

When the person has recovered from post-traumatic amnesia, the long-term difficulties will become more apparent and you can start to think about how to cope with them. The best way to do this is through a combination of rehabilitation and selfhelp strategies.



Rehabilitation - speech and language therapy

Speech and Language Therapists (SLTs) specialise in the management of speech, language, communication and swallowing disorders. They may work alone, or as part of a multidisciplinary team consisting of Physiotherapists, Psychologists, Occupational Therapists and others.

SLTs usually work in local hospitals, rehabilitation units and community brain injury teams, while some work in private practice. Referrals can come from the hospital or GP. A directory of professionals in private practice, with details of their areas of specialism, is available from the Royal College of Speech and Language Therapists and from the Association of Speech and Language Therapists in Private Practice.

Assessments are conducted in order to find out how communication skills are affected. The SLT will want to meet with the person and their family in order to gain a full picture of the person's life before the injury. This will include taking a case history to find out about their personality, work and leisure preferences. This information is important as it helps identify:

How the person's lifestyle has changed since the injury
How the injury may affect future plans, e.g. work, independence, social life

The Speech and Language Therapist will assess speech and language skills in order to identify changes in any of the areas outlined in this booklet. They will then devise a therapy programme based on the assessment findings. Due to the close interplay with other cognitive skills, an assessment also involving others in a multi-disciplinary team will give the fullest information.

The SLT's key role is to help the person communicate as successfully as possible. This may involve providing therapy, information and strategies to help the person and their carers to address the problems. While some individuals may progress sufficiently to resume some or all prior activities (e.g. work), this level of recovery is not always a realistic goal.

While SLTs are an invaluable source of help, sadly in many cases appointments may be restricted in number or unavailable. Fortunately, there are things that you can do to help even without professional input.

Living with communication problems

It's so frustrating when I just can't find the words for people, places or objects. I just want to shake myself and make the rights words come out, but the angrier I am the worse it seems to get.



Long-term communication difficulties

The degree and type of long-term communication problems after brain injury will depend on the location and severity of the injuries. The following categories cover the main problems:

- Altered levels of consciousness includes the early period of coma and reduced awareness states such as 'vegetative state' and 'minimally conscious state'
- Language difficulties (aphasia) linked with specific damage to the parts of the brain responsible for understanding and using anguage
- Speech difficulties linked with altered control over the nerves and muscles responsible for speech
- Cognitive communication difficulties linked with altered cognitive skills, e.g. attention problems, memory difficulties and impaired ability to understand and use social knowledge

Brain injury, particularly traumatic injury, frequently affects more than one area of the brain. Because of this, combinations of language difficulties, speech difficulties and cognitive communication difficulties are common.

A Speech and Language Therapist can identify the person's individual pattern of communication difficulties.

Altered levels of consciousness

After very severe brain injuries, some people remain in an altered level of consciousness called a vegetative state. Typically, such individuals will seem unresponsive and unaware of their environment.

There are several other recognised levels of consciousness. Some individuals may show some intermittent and limited awareness and/or responsiveness to their environment. This condition is called minimally conscious state. A detailed assessment can identify the nature of the condition and the level of awareness. The assessment determines the individual's level of responsiveness to controlled external stimuli, e.g. sound, light, touch and odour. These assessments usually involve a number of sessions across a period of weeks and at different times throughout the day.

Often, staff from varied clinical backgrounds, including Speech and Language Therapists, will be able to carry out such assessments. There are a number of assessment tools, such as the Sensory Modality Assessment and Rehabilitation Technique (SMART). Assessment may lead to confirmation of a vegetative state or to the identification of any form of meaningful response (e.g. pressing a switch to indicate yes or no). It may then be possible to build upon these responses.

The staff will aim to establish whether or not movements made by the person are happening in response to what they see, hear, etc. This is because some patterns of movement can happen at intervals even when no such trigger has occurred. For this reason, it is important not to interpret all movements, such as raising the hand or blinking, as signs of responsiveness. It is worth noting that some people in PVS may appear to smile, laugh, grimace or groan. Such actions are often interpreted as happiness, pain, discomfort or displeasure, which can be very distressing for relatives. In fact, they are usually just reflex actions rather than conscious responses. It is important to seek the advice of the staff about whether any specific movements or gestures are true responses.

Should an individual make progress beyond this level, the Speech and Language Therapist will be able to offer advice regarding suitable communication aids (see the 'Communication aids' section for more information).

Tips:

- Ask for advice on how to be alert for behaviours that may be true responses
- Talk to staff about how best to stimulate responses and whether the responses can be used in order to communicate
- Talk for short periods about things of interest to the person
- Keep communication clear and simple and speak in the way you normally would
- Use different kinds of communication, such as playing taped messages or their favourite music (this needs to be cleared with staff and may not be possible in shared rooms)
- Use varied types of interaction, following guidance from staff e.g. touch, music and reading
- Try not to bombard the person with information, loud music, bright lights or noisy toys in an attempt to stimulate them
- Avoid having too many visitors around the bed area at the same time

- Introduce visitors by name and allow them to say hello one at a time
- Aim for only one person speaking at any one time

Language impairment – aphasia

Injury to language centres of the brain leads to a condition called **aphasia**. There are different levels of impairment and the term **dysphasia** refers to partial loss of language. However, in practise, the terms are interchangeable and here we will simply use the term aphasia.

Wernicke's area and Broca's area are two regions of the brain that are important for understanding and using language. These areas are found in the dominant side of the brain and for most people, particularly right-handers, they are in the left hemisphere. Injury to these areas leads to two main forms of aphasia: receptive aphasia and expressive aphasia.

The locations of these areas are shown in the diagram on page three.

In practise, it is quite rare for pure receptive or expressive aphasia to occur. Strokes can be associated with damage to very specific areas of the brain, including the language areas, so can cause very specific symptoms. However, most forms of acquired brain injury affect several brain regions and cause a combination of difficulties. A Speech and Language Therapist will be able to assess individual patterns of aphasia. Treatment may then involve a mixture of therapy, advice and strategies.

Receptive aphasia

Receptive aphasia is an impairment of the understanding of language. This usually occurs because of damage to **Wernicke's area**, so it is sometimes referred to as Wernicke's aphasia.

The term receptive aphasia is actually slightly misleading because the condition also affects aspects of speech output. People with receptive aphasia usually retain the ability to speak fluently and the term **fluent aphasia** is sometimes used. However, the content of speech is often jumbled or lacking meaning.

In its most severe form, the person will not recognise spoken and/or written words. They will not be able to understand sentences or follow conversations. However, usually people will retain some understanding. For example, the person may recognise some but not all words, or simple but not complex sentences. It may be that familiar words still have meaning (e.g. pill), but that less frequently used words are no longer understood (e.g. medication). The person with receptive aphasia may have better ability in one area than another (e.g. they may be able to recognise written words more readily than spoken ones, or vice versa). They may also have retained some non-verbal skills (e.g. they may recognise gestures or pictures). Therefore, using nonverbal forms of communication may help the person's understanding.

As noted earlier, receptive aphasia also affects aspects of speech output. People may speak in long chains of words that have limited meaning (gibberish), use incorrect words, or unintentionally create made-up words. The problem with understanding language means the person may be unaware of their errors and expect the listener to respond.

Usually, when unable to think of a word, people can describe it instead, e.g. "oh, you know...it is a pet...and it barks!" It may be harder for someone with receptive aphasia to use this strategy, as they may not be able to effectively link 'meaning' with the object or person.

Reading problems

Problems with reading, when evident, may reflect the receptive spoken language issues. E.g. the person may:

- Be unable to recognise individual letters
- Be unable to recognise written words
- Read but not understand familiar words
- Be unable to fully understand simple written sentences

It is important to be aware that reading problems may also arise due to other difficulties, such as altered vision. Advice needs to be specific to the individual, and provided by the relevant specialist, e.g. an Orthoptist. Common strategies include enlarging print size, selecting a clear font, using a line guide to support looking at the full line of print, and increasing contrast between paper and print, e.g. black type on yellow paper.

Tips for carers:

- Make sure the environment is quiet and free of distractions
- Understand that you will be primarily responsible for guiding the conversation
- Be patient and don't expect immediate responses
- Try to make sure you are both relaxed and have plenty of time when communicating
- Make sure you have the person's attention before speaking
- Think about your word choice it may help to use simple words, such as 'pills' rather than 'medication'
- Use simple sentence structures, but not as if talking to a child
- Speak clearly and pause normally at the ends of phrases and sentences
- Repeat or rephrase things when needed
- Avoid asking more than one question at a time
- Be aware of signs that the person is becoming overwhelmed or confused – signs may include lack of response, a vacant expression or obvious distraction
- Consider using non-verbal methods to aid the person's understanding, e.g. gestures, pointing, pictures or sketches
- Consider writing down key words
- Encourage the person to summarise what they have understood before moving on or changing the subject – this helps you to be aware of and sort out any misunderstandings

- Make it clear through pauses, gestures, etc, when you are moving from one topic to another
- Don't keep conversations going for longer than the person is comfortable
- Support the person in engaging in as broad a range of social activities as possible

Tips for people with receptive aphasia:

- Make sure the environment is quiet and free of distractions
- Communicate when you are relaxed and have plenty of time
- Write down key points you want to make ahead of the conversation – you could give the list to the other person so they can prompt you
- Let the other person know when you have lost track
- Try to summarise what you have understood at key points in a conversation – you could try writing down (or asking the other person to write down) key points in a way you understand so you can refer to them later
- Don't pretend to understand when you haven't
- Ask for things to be rephrased or repeated when you don't understand
- Ask people to use your preferred non-verbal methods, such as gestures, sketches, simple writing, etc

Expressive aphasia

Expressive aphasia is an impairment of the ability to use and express language. This is caused by damage to Broca's area, so the condition is sometimes referred to as **Broca's aphasia**. In its most severe form, the affected person may be unable to

produce any meaningful speech. More commonly, speech output may lack fluency with relatively few words used. The speaker will use short, simple sentences, broken up by frequent pauses. However, they may be able to understand language normally and be aware of their own difficulties.

Output may be a struggle, but sometimes an individual can provide accurate, if limited, information. Speech may be 'telegraphic', omitting small words such as 'the'. So, 'tomorrow I'm going to the pub with my wife for our anniversary', may be expressed as 'tomorrow...pub... wife... anniversary'. This requires the listener to accurately piece the message together.

The person may struggle to name objects or people, even when aware of what or who they are. This can be extremely frustrating and cues or reminders may not work if the brain is simply unable to produce the correct output.

Writing problems

Problems with writing, when evident, may reflect the expressive spoken language issues.

For example, the person may:

- Be unable to write down a specific letter of the alphabet
- Write words with letters in the incorrect order
- Write down incorrect words, which are still connected to the intended ones, e.g. they may write 'wife' when they needed to write 'daughter'
- Be unable to write simple sentences

Writing problems may also arise due to other difficulties, such as altered vision and/or reduced physical control of the pen or pencil. Advice needs to be specific to the individual, and provided by the relevant specialist, e.g. an Orthoptist or Occupational Therapist. Common strategies include using a line guide to support writing across the full width of the page and writing with black ink on yellow paper to increase the contrast.

Tips for carers:

- Make sure the environment is quiet and free of distractions
- Try to have plenty of time for a conversation so you aren't both rushed and stressed
- Try to make sure you are both relaxed when communicating
- Encourage the person to use non-verbal skills to convey their message, e.g. gestures, pointing, pictures or sketches
- Agree signals or gestures for words or phrases the person uses often, such as 'yes' and 'no'
- Do not pretend to understand when you have not
- Feedback parts of the message that you have understood so that the person knows what they need to repeat
- If you are both struggling, try to agree an 'end point' to reduce spiralling frustration
- Do not push the person for a level of accuracy that may not be achievable
- Support the person in engaging in as broad a range of social activity as possible

Tips for people with expressive aphasia:

- Avoid unnecessary background noise during conversations
- Try to make sure you are relaxed and not rushed when communicating
- Use non-verbal methods of communicating, such as pictures, gestures and drawings
- If your writing is better than your speech then consider using writing to support getting your message across successfully
- Identify simple key words and phrases that are easy to say and you can use often, e.g. "tea please!"
- Try not to force yourself to say a specific word or phrase if you are struggling – try a different way of expressing the idea
- Be positive and focus on your successes

Speech difficulties

Sometimes brain injury causes communication difficulties by impairing the physical ability to speak, rather than the ability to understand and express language. The two main speech disorders are **dysarthria** and **dyspraxia of speech**.

Living with communication problems

It makes so much difference to talk to someone who is patient and understanding. My husband and I have a policy of making sure we understand each other before we move on to another subject and we are always honest with each other when we don't understand something. That way we can work out a better way of getting the message across.

Dysarthria

Dysarthria occurs when there is damage to parts of the nervous system involved in the control of muscles used for speech. It can also occur because of injury or weakness more directly affecting the muscles themselves. Dysarthria results in reduced control and clarity of speech.

When dysarthria occurs in isolation, a person's ability to speak will be impaired, but their ability to understand language and construct sentences will be intact. However, in practise there are often elements of both aphasia and dysarthria present.

Features may include:

- Reduced movement (range or strength) of the lips, tongue, and soft palate
- Problems controlling the flow of air from the lungs when speaking
- Difficulty in producing varied and controlled changes in the volume of speech
- Difficulty in producing varied and controlled patterns in the tone of speech
- Slurring of speech

Tips for carers:

- Avoid unnecessary background noise and interruption
- If the person's understanding is unimpaired then don't patronise them by simplifying your own speech
- Allow sufficient time for the person to get their message across
- Don't rush to make assumptions about what the person is trying to say, but be willing to have a guess

- Position yourself so you can watch the person as they speak
 you may pick up clues about the words attempted from their mouth shapes
- If you don't understand a word ask them to spell it or write it down
- Ask for repetition of any words you have missed, e.g. "where did you say you went last night?"
- Repeat back so the person can then confirm either that you have understood them or correct any misunderstandings, e.g. "did you say you went to the supermarket last night?"
- If they are able, encourage the person to slow down the pace of their speech – this gives them time to form the words as clearly as possible
- If they are able, encourage the person to 'over-articulate', aiming to be very accurate and not omitting any of the middle or end sounds, e.g. 'hip-po-po-ta-mus' not 'hippomus'
- If they are able, encourage the person to split long words up into syllables, e.g. sup-er-mar-ket
- Prompt the person to use key words or short sentences
- Encourage the person to use natural aids to communication, e.g. gestures, pointing, writing words down
- Encourage the person to use any communication aid that has been provided

Tips for people with dysarthria:

- Think about your posture try to adopt as good a position as possible when speaking (as upright as possible, with your head in the midline is best)
- Try to ensure you have adequate time for important conversations, e.g. book double appointment slots
- Agree clear signals for 'yes' and 'no' and for words or phrases that you need to use regularly

- Feel confident to use strategies such as writing, spelling tricky words aloud, using gestures, etc.
- If you tend to run out of breath (or your voice becomes quieter) when you say a long sentence, take breaths within it
- Aim to 'chunk' sentences into smaller but grammatical sections, e.g. 'the doctor // gave me // these pills' will be easier to understand than 'the // doctor gave // me these // pills'
- Ask your listeners to let you know if they have not fully understood, e.g. "did you catch where I said I went last night?"
- Ask your listeners to check any words they may have missed so you can correct any misunderstanding

Dyspraxia of speech

Dyspraxia is a disorder of planned and co-ordinated movement. It occurs because of injury to areas of the brain responsible for conscious movement, mainly situated in the frontal lobes.

Dyspraxia of speech causes people to have difficulty saying what they consciously intend to say. However, some individuals may be able to speak perfectly normally when not thinking about it, for example, if someone asks them a question and they have to respond spontaneously. Long words tend to be more difficult to say then short words for some people with dyspraxia of speech.

The disorder can range from mild in some people to very severe in others.

Tips for carers:

- Do not pressurise the person to try to repeat any successful spontaneous words (this takes it from being spontaneous to a 'planned' movement, which may be far harder to achieve, and thus lead to increased frustration)
- Respond to speech attempts that you have understood focus on their success in having got their message across
- Encourage the person to select and use short, simple words and sentences
- Avoid unnecessary background noise and interruption
- If the person's understanding is unimpaired then don't patronise them by simplifying your own speech
- Allow sufficient time for the person to get their message across
- Don't rush to make assumptions about what the person is trying to say, but be willing to have a guess at appropriate points

Tips for people with dyspraxia of speech:

- Use short, simple words and sentences that you're comfortable with
- If certain sounds or sound sequences are easier for you than others (e.g. 'b') make good use of them, e.g. 'bed' may be easier to say than 'sleepy' or 'tired'
- Use non-verbal methods to get your message across, e.g. gestures, alphabet charts, pictures and objects
- Ask people to let you know if they haven't fully understood
- Try to ensure you have adequate time for important conversations, e.g. book double appointment slots

- Agree clear signals for 'yes' and 'no' and for words or phrases that you need to use regularly
- Feel confident to use strategies such as writing, spelling tricky words aloud, using gestures, etc.

A Speech and Language Therapist will be able to identify and assess dysarthria and dyspraxia of speech. Recovery and degree of difficulties will depend upon the severity of the initial brain injury. However, for a variety of reasons (e.g. presence of other difficulties), individuals may respond differently to therapy. Some people will make more progress than others, despite having had a similar injury.

In severe cases, those with speech difficulties may be unable to achieve recognisable speech. In such cases, they may benefit from the use of an Augmentative Aid to Communication (AAC). The section on communication aids at the end of the booklet describes these in more detail.

Living with communication problems

My wife finds it so much easier to make herself understood by using little pictures and diagrams, so we always have a drawing pad in front of us when we talk. We make sure we have plenty of time available in the evening and catch up on what she's been doing with her support worker that day.

Cognitive communication difficulties

Communication is a complex process, which involves many aspects of thinking and social skills. If brain injury impairs any of these skills then it can affect the ability to communicate successfully. 'Cognitive communication difficulties' is the term most often used for the resulting problems. The frontal lobes are particularly important for cognitive communication skills because of their role in the brain's 'executive functions', including planning, organisation, flexible thinking and social behaviour. However, many other parts of the brain interact to perform the skills and are also important, such as areas of the temporal and parietal lobes.

This type of communication difficulty reflects a range of potential cognitive changes, such as:

- Attention and concentration difficulties
- Memory problems
- Literal interpretation
- Reduced reasoning and problem-solving skills
- Cognitive fatigue
- Slowed speed of information processing
- Impaired social communication skills
- Reduced insight

Attention and concentration difficulties

Problems in this area can contribute to a range of communication difficulties. For example:

The person may not be able to concentrate to watch a TV programme that they used to enjoy. They may begin to chat, thus affecting other people's enjoyment of the programme.

- They may have difficulty concentrating on conversations. This could cause them to end conversations abruptly or avoid them altogether.
- Failure to pay attention can lead to the person missing important information. This can cause them to say inappropriate and embarrassing things. For example, you may have told them that a friend's pet has died but if they were unable to pay full attention, they might still ask the friend how their pet is.
- Dividing attention between two or more activities may be difficult. For example, the person may ignore what someone says when carrying out another activity at the same time. This may appear rude to people who do not understand.

Living with communication problems

I find busy social occasions overwhelming but my friends are really helpful and understanding. They make things easier by making sure they talk one at a time and giving me chance to have my say. They do have a tendency to switch from one subject to another very quickly! However, if I'm honest and let them know when I've lost track then I can usually pick things up again.

Memory problems

A person with memory problems may find it hard to access information that they 'know'. This can affect skills such as word recall and remembering people's names, which are very important when communicating socially. The failure to remember names or faces at a party, or information relevant to a conversation, can cause embarrassment and can lead to people avoiding social situations altogether.

Living with communication problems

I find that a small pocket-sized notebook is vital for maintaining sanity. Here I can jot down the important things I need to say. A pencil can be tied to the book so that it doesn't get lost.

Literal interpretation

Damage to the right side of the brain may lead to the person interpreting verbal information very concretely and taking things literally. They may have a reduced ability to grasp humour or sarcasm and may miss the subtle nuances of conversation. This type of difficulty can result in the person taking things the wrong way. For example, a joking "What time do you call this to come home at night?!" could be taken seriously and lead to an argument.

Similarly, it can make it hard for the person to understand common expressions. For example, if you use an expression such as "I'll just be a minute" they may take it literally and get upset if you take longer than one minute.

Reduced reasoning and problem-solving skills

Altered problem-solving ability can result in the person being unable to use language to think through and resolve a problem (e.g. how to get home having missed the last bus). This can cause them to make poor judgments or decisions (e.g. setting out to walk home alone in the dark, rather than a wiser alternative such as ringing home for a lift).

Impaired reasoning and problem-solving skills can also lead to people experiencing difficulties in their conversational style. They may fail to understand the logic of someone's point of view, and be inflexible in their own opinions.

Cognitive fatigue

Cognitive fatigue is a common long-term consequence of brain injury. Once fatigued, the person will often manage less well with their cognitive communication skills. Attention and concentration will be reduced, they will be less able to think clearly and they may become irritable and agitated. Fatigue can also make other communication impairments worse, e.g. aphasia, dysarthria and dyspraxia of speech.

Slowed speed of information processing

This is again a common consequence of brain injury, and may mean that the person cannot keep up with a rapidly flowing conversation. Often the person will comment that this is most difficult in busy settings, or when talking with more than one person. This can result in them becoming 'overloaded' with information. They may then become overwhelmed and 'switch off', or get frustrated and angry.

Impaired social communication skills

Social communication difficulties are particularly associated with injury to the frontal lobes of the brain. Difficulties in this area can mean the person does not recognise everyday social cues, both verbal and non-verbal. For example, they may not realise that someone is uncomfortable with the topic of conversation or that they are in a hurry to leave.

There are a number of widely accepted 'norms' of social behaviour within any culture. Brain injury may affect a person's ability to recognise and adhere to these norms effectively. They may say the wrong thing at the wrong time and come across as rude or aggressive, e.g. saying "Look at her! Isn't that coat horrible!" in a loud voice on the bus.

Other potential problems with social communication may include:

- Altered turn-taking skills (e.g. the person either being overly talkative and 'hogging' the conversation or not realising that it is their turn to speak)
- Interrupting someone else because they are afraid that otherwise they will forget what they want to say
- Altered ability to talk around a shared topic (e.g. flitting from topic to topic, or having a reduced range of topics)
- Speaking only about themselves and fixating on certain subjects
- Talking in a sexually explicit way or swearing at inappropriate times
- Perseverating (getting stuck) on a favoured topic (e.g. wishing to leave hospital)
- Altered ability to give information in an orderly and organised way (e.g. assuming the other person shares knowledge about the topic when they don't, or vice versa)
- Not using or 'reading' non-verbal cues accurately, such as facial expressions and body language

Reduced insight

The person may lack or have limited insight into any or all of these problems. They may believe they are acting 'normally' and exactly as they would have done before. This can be hard for those interacting with them. If the person lacks insight, it makes changing the problematic behaviours extremely difficult because it is hard for them to deal with a problem if they don't know there is one.

Coping with cognitive communication difficulties

Any of the above problems can have a significant effect on how easily the person copes with everyday life. It is, however, often hard for others to recognise these difficulties as being part of the brain injury. The person may seem obstinate, bad tempered or aggressive. Their responses may be inappropriate and completely different to the person's behaviour prior to the injury (e.g. swearing in public). It is therefore important to recognise these underlying difficulties, and to be aware of strategies that may help.

Tips for carers:

- Ensure the person's attention is on you before giving information or instructions
- Where possible, make things more predictable by developing a consistent routine
- Decrease distractions, aiming for a quiet and relaxed setting
- Break down instructions and information into small steps
- Give the person time to process what you have said
- Look out for signs of fatigue let the person 'opt out' for a while rather than expect them to continue fully in the conversation
- If the person has some level of insight into their problems, discuss how and when they would like you to give feedback, e.g. on any success or difficulty they have had in conversing
- Support the person in having varied communication opportunities to prevent social isolation
- Encourage the person to let you know if they are finding a social setting difficult
- Encourage them to move away from a difficult situation in order to reduce the chance of them becoming overwhelmed or angry

- Ask questions and use reminders to help the person stay on topic
- Make it clear when you are moving to a new topic
- Avoid sarcasm, and use of non-literal expressions
- Encourage the person to make eye contact when talking, as long as they don't find it too stressful
- Support the person in the use of diaries, wallplanners, notepads, smartphones, voice recorders, Post-It notes or any reminder system that suits them
- Be aware of any related cognitive problems that may affect the person's independent use of strategies, e.g. someone with a memory problem may need help with remembering to write something down or where to put their diary
- Make it clear when their behaviour is socially unacceptable or offensive – try to do this discretely and in private

Tips for people with a brain injury:

- Avoid rushing so you have enough time available for important conversations, e.g. ask for a double slot for appointments
- Try to anticipate situations where communication may be difficult – try to build up from easy to more difficult situations gradually (e.g. a coffee for two in a small cafe may be easier than attending a busy wedding reception)
- Try to use diaries, wallplanners, notepads, smartphones, voice recorders, Post-It notes, or any kind of reminder systems that suit you
- Be prepared to ask for help to use such reminder systems to best effect
- Aim to establish set places to keep important things in order to reduce demands on memory

Coping with communication problems after brain injury

- Practise using your reminder systems as much as possible so they become second nature
- Listen to feedback from others about your social interactions. Try to act on previous feedback when in similar situations again
- Think about others when in a public environment
- Try not to talk too loudly or swear, especially when with new or unfamiliar people
- Be alert to other people changing the subject during a conversation – try not to carry on talking about the previous topic
- Try to rest and avoid stressful situations when you recognise signs of fatigue
- Try to schedule demanding social situations (e.g. appointments) at times when you feel at your most awake and alert
- Try to do one thing at a time if possible
- If you have missed part of a conversation, then be honest and ask the people to repeat themselves – most people will be perfectly understanding about this when they know that concentration can be difficult for you
- Try not to dwell on social mistakes and don't let them put you off social situations – other people will usually be understanding and will often just forget about it anyway

You can find further useful information on this subject in several publications available from Headway. The factsheet *Executive dysfunction after brain injury* would be a useful starting point.

Living with communication problems

The changes in my husband's social skills can be very embarrassing as he says the most inappropriate things to people! I have to remind myself that it isn't his fault and that he really can't help it. It's best to just get on with things because it would be worse for his quality of life if he just avoided social situations altogether.

It helps if I let him know when his behaviour is really unacceptable. I usually take him to one side and tell him rather than making things even more embarrassing. It's also helpful for his friends to be aware of the problem and for their reactions to be consistent with mine. His friends know now not to laugh and encourage him when he says inappropriate things.





Communication aids

The Speech and Language Therapist may suggest that an Augmentative Aid to Communication (AAC), also known as a communication aid, may be of benefit. Sometimes this is a short-term need (e.g. an alphabet chart for someone who has a tracheostomy), while people with persisting problems may have a long-term requirement. For some individuals, learning alternative forms of communication (such as sign language) may be helpful.

There are many types of communication aids, including:

- Low-tech options (e.g. alphabet boards and picture charts)
- High-tech aids (e.g. dedicated communication devices, computer-based systems and amplifiers)

The type of aid selected must be suited to the overall needs of the individual. The following factors are important:

- Any physical difficulty which could affect the person's ability to use aids
- Positioning of the communication aid
- Required level of portability of the aid e.g. does the person need to be able to take it out with them, or use it only in the house?
- Any visual difficulty (which would affect the size and number of images used on the aid)
- Cognitive skills (which could affect the difficulty of learning to use the aid)
- Psychological factors for example, if the person is very distressed it may affect their ability to concentrate, remember and learn effectively

 Preference and motivation (the person needs to believe that the aid provides them with something that spoken language alone doesn't)

Many modern aids are able to accommodate variable levels of ability and need, ranging from making simple yes/no decisions through to complex uses of language (e.g. people have written whole books using simple eye-pointing alphabet charts).

Here is an example of a simple alphabet chart:



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You can find further information about communication aids, and about choosing and funding them, from a Speech and Language Therapist and from some of the organisations listed in the back of this booklet.

Summary

The ability to communicate in both verbal and non-verbal ways is something that most of us take for granted. However, the physical, emotional, cognitive and behavioural effects of a brain injury can all affect this ability in different ways.

This booklet has outlined the main communication difficulties caused by brain injury and provided information to help you compensate. We hope you have found this helpful and that you can continue to apply the strategies in everyday life. Nothing can make things easy, but there are ways of communicating effectively even with severe verbal, non-verbal and social communication impairments.

Finding help so that you don't have to cope with the situation alone can make a huge difference to your quality of life. The rest of this booklet provides suggestions for publications that you may find helpful and details of other organisations that can provide information and support.

You can also contact the Headway helpline to discuss any of the issues raised here. Please call **0808 800 2244**, or email **helpline@headway.org.uk**. Our trained staff can provide a listening ear and can send you further information free of charge.

Frequently asked questions

I find it hard to keep up with conversations. This is even harder when I am in a busy place, or with a group of friends, where there may be more than one conversation going on. I often say things a bit too late, when the conversation has moved on, or I just stop listening, as I get overwhelmed. What can I do?

This type of problem can make you feel very isolated and 'different'. Some people find it can help if they let others know they have a problem. It may help if you let your friends know what you find hard, and how it makes you feel. They may assume that you are just choosing to be quiet because you have nothing in particular to say! They may well be happy to adjust the speed of conversations slightly, or to aim for discussing just one topic at a time.

Ask friends to watch your body language, (such as raising an index finger when you have something you want to say) so that they do not rush on before you have your turn. You may also find it useful to think of a few conversational topics before going out, so that you can be the person who starts the ball rolling (e.g. asking a friend about a holiday they have just been on, or the date they had last week).

You can find some examples of useful strategies in the 'Cognitive communication difficulties' section of this booklet. My husband gets angry when I make sarcastic comments, and really hung up on things such as me getting home at a certain time. Before his brain injury, he used to be relaxed and see the funny side of things. Now he gets argumentative and then just shouts at me.

Your husband may have problems in understanding humour or sarcasm and may be taking what you say literally. Therefore, he may take a comment such as "I'm going to the shops, I'll just be a minute" at face value. This may trigger his angry reaction, as he will expect you back in one minute. He may also take good-natured teasing as genuine insults.

Avoid giving specifics. For example, you could just say, "I'm going to the shops", or, if you are sure you will achieve it, try giving a range, e.g. "I'll be back between 5 and 6 pm". Give information clearly rather than giving indirect hints or teasing. For example, just say "please make yourself a cup of tea", rather than a light-hearted "what did your last slave die of?!"

You can find some examples of useful strategies in the 'Cognitive communication difficulties' section of this booklet.

My son sustained a head injury and has very slurred speech. He sounds as if he has been drinking. It gets worse when he is tired. Can a Speech and Language Therapist help?

The amount of change possible in your son's speech will depend a lot on the severity of the injury, and how long has passed since then. Most active recovery tends to takes place in the weeks and months after the injury. A Speech and Language Therapist may be able to offer direct therapy to maximise this early progress. At later stages, they can help to develop a range of useful strategies that you, your son, family and friends can use. You can find some examples of such strategies in the 'Dysarthria' section of this booklet.

My wife has aphasia following a brain injury. She tries to tell me what she has been doing during the day when I am out at work, but she just cannot find the right words. If I ask her something such as "have you been to the shops with your support worker?" then she can say "yes" or "no" but you can see she is frustrated at having to do this. She just wants to be able to tell me herself. What else can I do to help?

Does your wife recognise pictures or written words? If so, you could work together to develop a set of pictures or a word list that covers the types of things she typically does each day. You could then look at this together and she can point out the things she has done. Also, your wife's support worker could jot down a list of the day's activities. You can look at this together as a starting point for your conversation.

You can find examples of possible strategies in the 'Receptive aphasia' and 'Expressive aphasia' sections of this booklet.

Further reading

The following books are available from Headway and provide a good introduction to brain injury and its effects:

- Clare, L. & Wilson, B.A (1997) Coping with Memory Problems: A practical guide for people with memory impairments, their relatives, friends and carers. London: Pearson Assessment.
- Daisley, A., Tams, R. and Kischka, U. (2008) Head Injury: The Facts. Oxford: Oxford University Press.
- Hedley, N (2011) Living with an Acquired Brain Injury: The Practical Life Skills Workbook. Milton Keynes: Speechmark Publishing Ltd.
- Johnson, J. (2013) *My Dad Makes the Best Boats.* Milton Keynes: Speechmark Publishing Ltd.
- Johnson, J. (2013) My Mum Makes the Best Cakes. Milton Keynes: Speechmark Publishing Ltd.
- Johnson, J. (2011) "My Parent has a Brain Injury..." ...a Guide for Young People. Self-published.
- Powell, T (2013) The Brain Injury Workbook: Exercises for Cognitive Rehabilitation.
 - Milton Keynes: Speechmark Publishing Ltd.
- Powell, T. (2004) Head Injury: A Practical Guide. Milton Keynes: Speechmark Publishing Ltd.

The aphasia charities Speakability and Connect produce a wide range of publications to help people with aphasia. Contact details are in the 'Useful organisations' section of this booklet.

The following books provide information on aspects of speech, language and communication difficulties. They are available from the Headway Amazon shop.

- Bauby, J. (1997) *The Diving-Bell and the Butterfly.* Hale, S. (2007) *The Man who Lost his Language: A Case of Aphasia.* Jessica Kingsley Publishers.
- Parr, S. (2004) The Stroke and Aphasia Handbook. Connect Press.
- Parr, S., Byng, S., Gilpin, S. & Ireland, C. (1997) Talking about Aphasia: Living with Language Loss after Stroke. Open University Press.
- Wahrborg, P. (1992) Assessment and Management of Emotional and Psychosocial Reactions to Brain Damage and Aphasia. West Sussex: Wiley Blackwell.

Headway also produces an extensive range of booklets and factsheets.

For more information, please visit our Headway shop, or telephone **0115 924 0800**. Brain injury survivors and carers can receive free copies of appropriate booklets from the Headway helpline on **0808 800 2244**.

The following titles are of particular relevance to the information in this booklet:

Booklets

Caring for someone with a brain injury
Hospital treatment and early recovery after brain injury
Managing anger after brain injury
Managing fatigue after brain injury
Memory problems after brain injury
Minor head injury and concussion
Psychological effects of brain injury
Redeveloping skills after brain injury

Factsheets

About the brain
Brain injury and epilepsy
Coma and reduced awareness states
Coma stimulation - suggested activities
Coping with memory problems - practical strategies
Difficulties with decision making after brain injury
Executive dysfunction after brain injury
Hormonal imbalances after brain injury
Hypoxic brain injury
Loss of taste and smell after brain injury
Post-traumatic amnesia
Returning to work and education factsheet pack

Useful organisations

1Voice Tel: 07943 618 525 Web: www.1voice.info

Ability Net

Tel: 0800 269 545 Email: enquiries@ abilitynet.org.uk Web: www.abilitynet.org.uk

Afasic Cymru

Helpline: 0845 3 55 55 77 Web: www.afasiccymru.org.uk

Afasic England

Helpline: 0845 3 55 55 77 Web: www.afasic.org.uk/

Afasic Northern Ireland Helpline: 0845 3 55 55 77 Web: www.afasicnorthern ireland.org.uk

Afasic Scotland Helpline: 0845 3 55 55 77 Web: www.afasic scotland.org.uk Aphasia Now Web: www.aphasianow.org

Association for Rehabilitation of Communication and Oral Skills (ARCOS) Tel: 01684 576795 Email: admin@arcos.org.uk Web: www.arcos.org.uk

Association of Speech and Language Therapists in Independent Practice Tel: 01494 488306 Web: www.helpwithtalking.com

British Aphasiology Society Web: www.bas.org.uk/

British Dyslexia Association Helpline: 0333 405 4567 Email:helpline@bdadyslexia.org.uk Web: www.bdadyslexia.org.uk/

Coping with communication problems after brain injury

Communication Matters Tel: 0845 456 8211 Email: admin@communication matters.org.uk Web: www.communication matters.org.uk

The Communication Trust Tel: 0207 843 2526 Email: enquiries @thecommunicationtrust.org.uk Web: www.thecommunication trust.org.uk

Connect - the communication disability network Tel: 020 7367 0840 Email: info@ukconnect.org Web: www.ukconnect.org

Disabled Living Foundation (DLF) Helpline: 0300 999 0004 Email: helpline@dlf.org.uk Web: www.dlf.org.uk

Find a Voice – helping people communicate Tel: 01233 634 625 Email: speak@findavoice.org.uk

Web: www.findavoice.org.uk

Health & Care Professions Council (HCPC) Tel: 0845 300 6184 Web: www.hpc-uk.org

I CAN Tel: 0845 225 4071 Email: info@ican.org.uk Web: www.ican.org.uk

Royal College of Speech and Language Therapists Tel: 020 7378 1200 Email: info@rcslt.org Web: www.rcslt.org.uk

Speakability Tel: 020 7261 9572 Helpline: 080 8808 9572 Email: speakability@ speakability.org.uk Web: www.speakability.org.uk

Stroke Association Tel: 0303 3033 100 Email: info@stroke.org.uk Web: www.stroke.org.uk

Talking Point Tel: 0845 225 4071 Email: info@talkingpoint.org.uk Web: www.talkingpoint.org.uk

How to donate

eadway – the brain injury association is a registered charity (1025852) and relies upon voluntary support to fund its work.

If you would like to help Headway by making a donation you can do so by donating online, contacting the Fundraising Team on **0115 924 0800** or sending a cheque to:

Headway - the brain injury association Bradbury House 190 Bagnall Road Old Basford Nottingham NG6 8SF

Alternatively, you can make a donation of up to $\pounds 10$ by texting **Head01** and the amount you wish to donate **70070**.

Internal areas of the brain and their functions



Hypothalamus

regulates the body's hormone production

Pituitary gland

controls the pituitary gland in order to regulate temperature, blood pressure, appetite, wakefulness and sexual arousal

Brain stem

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includes the midbrain, medulla and pons, controlling breathing, heart rate, consciousness, blood circulation, basic motor responses, relaying sensory information and regulating the sleep-wake cycle

About Headway

eadway – the brain injury association is a charity set up to give help and support to people affected by brain injury.

A network of local Headway groups and branches throughout the UK offers a wide range of services including rehabilitation programmes, carer support, social re-integration, community outreach and respite care. The Headway helpline provides information, signposts to sources of support and rehabilitation services, and offers a listening ear to those experiencing problems. Other services provided by Headway include:

- Supporting and developing local groups and branches
- Promoting understanding of brain injury and its effects
- An award-winning range of publications on aspects of brain injury
- Accreditation of UK care providers through the Approved Provider scheme
- A comprehensive, award-winning website
- Campaigning for measures that will reduce the incidence of brain injury
- Providing grants from our Emergency Fund for families coping with financial difficulties
- Headway Acute Trauma Support (HATS) nurses to support families with loved ones in hospital
- Freephone helpline: 0808 800 2244 (Monday–Friday, 9am–5pm)
- Telephone: 0115 924 0800
- Website: www.headway.org.uk
- Fax: 0115 958 4446
- Email: helpline@headway.org.uk

Coping with communication problems after brain injury

Caroline Prosser & Richard Morris

This booklet describes the many forms of speech, language and communication problems caused by brain injury. Practical strategies are provided for people with a brain injury, their families, carers and friends who are trying to cope with these difficulties.



the brain injury association

Web: www.headway.org.uk Helpline: 0808 800 2244