

A complete guide to communication
problems after stroke



A complete guide to

Communication problems after stroke



Problems with communication are common after stroke. This guide will help you understand more about them.

This guide explains why you may not be able to communicate properly after your stroke. It also explains how speech and language therapy can help. It tells you what you can do about communication problems and has tips to help other people support you.

It's aimed at people who have had a stroke but there is information for family and friends as well.

We have information on all aspects of stroke.

If you have a question that is not answered in this guide visit **stroke.org.uk** or call our Stroke Helpline on **0303 3033 100**.

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Why can't I communicate properly?

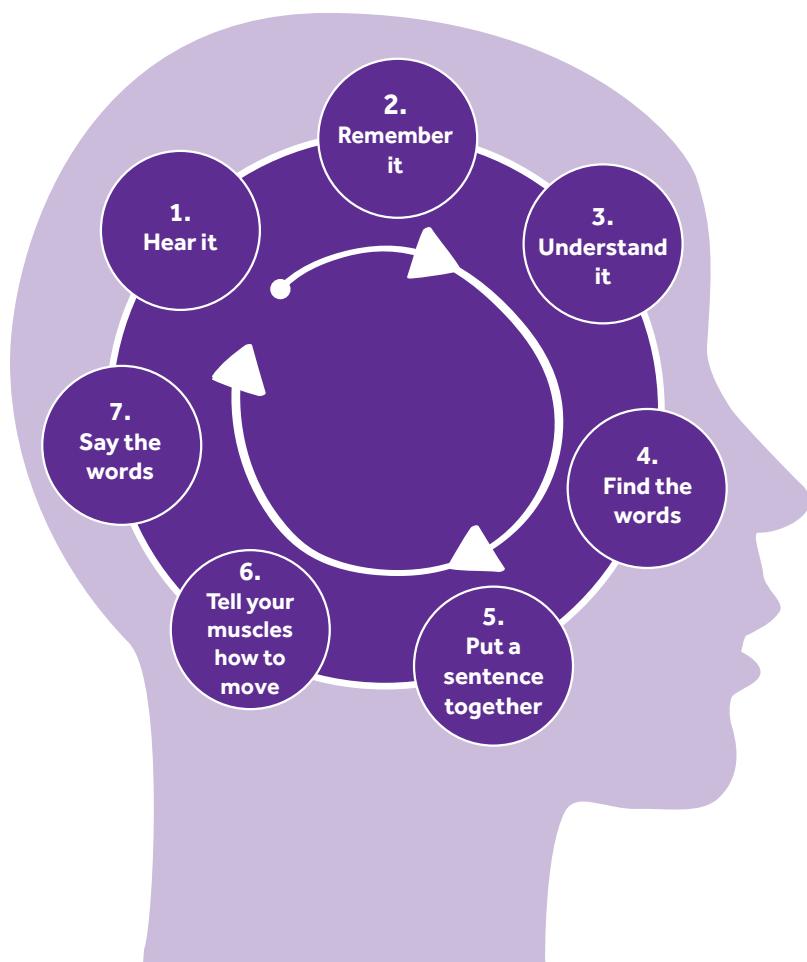
Communication problems happen after a stroke because of the damage to your brain.

When we communicate, our brain has to complete a series of tasks. So when someone asks you a question, your brain has to understand what you are being asked, decide on your answer and put the words together, before you can give them a reply.

Different parts of your brain carry out these tasks. Depending on the area of your brain that is damaged, you could have problems with any part of this process. Communication isn't just about speaking and understanding speech, however. Many people also have problems with reading, writing and using numbers.

Communication problems do not affect your intelligence

If you have communication problems you simply have problems with the process of speaking and sometimes understanding language. It has nothing to do with intelligence at all.



What happens when we're asked a question

What kinds of problems can this cause?

Aphasia

Aphasia affects your ability to speak and understand what others say. It can also affect your ability to read and write. Aphasia is sometimes called dysphasia.

It happens when the parts of your brain that control language are damaged. It does not affect your intelligence, although some people may treat you as if it has. Aphasia is a common problem after stroke. Around a third of stroke survivors have it.

There are different types of aphasia:

- **Broca's aphasia or expressive aphasia** is when it's very difficult to find the right words and say them, although you probably know exactly what you want to say. You may only be able to say single words or very short sentences, although it's usually possible for other people to understand what you mean. This can be very frustrating.
- **Wernicke's aphasia or fluent aphasia** is when you're able to speak well and use long sentences, but what you say may not make sense. You may not know that what you're saying is wrong, so you may get frustrated when people don't understand you.
- **Global aphasia** is when you have serious communication problems and you may not be able to speak, read or write at all.

**"Losing your communication
doesn't just affect you, it
affects everyone around
you too."**

Chris

Signs of aphasia

While it will be different for everyone, these are some of the more common signs of aphasia:

Problems speaking

- not being able to form words, only sounds
- only being able to say single words or very short sentences, like "want drink"
- speaking slowly, with very long pauses
- missing out words or getting them in the wrong order
- getting stuck on a single word or sound, and repeating it over and over
- saying one word when you mean another, so you may say "milk" instead of "water", or "yes" instead of "no"
- not being able to find the right word, even though you can describe what you're thinking of
- saying things that don't make sense.

Problems understanding

- not being able to understand much of what other people say.

Problems reading

- being able to read headlines in a newspaper, but not the rest of the text
- being able to write, but not read what you've written
- find reading difficult, because you're not able to recognise written words. This is sometimes called word blindness or visual aphasia.

Problems writing

- you may find it difficult to form letters, spell words, or write and type sentences in the right order|
- you may not be able to write or type at all.

Dysarthria

To speak clearly, we need to control the muscles in our face, mouth and throat as well as our breathing. Dysarthria happens when you're not able to do this.

Dysarthria is a physical speech difficulty. It doesn't affect your ability to understand other people or to find words and put them together, unless you have other communication problems at the same time.

Dysarthria is a common problem after stroke.

Signs of dysarthria

Dysarthria affects people in different ways. For some, their speech may only be a little unclear and people will usually be able to understand them. However, for others it means that they can't speak clearly at all.

Some common signs include:

- not being able to speak clearly
- slurred or slow speech
- speaking with a quiet or strained voice, or one that doesn't change its tone
- hesitating a lot or speaking in short bursts, rather than full sentences.

Apraxia of speech

Apraxia of speech is when you can't move the muscles in your face, mouth or throat in the right order. This can make it difficult for you to speak, and other people may struggle to understand you.

You may not have any weakness in these muscles and you may be able to control them individually without any problem. However, you can't move them in the way you want to when you try to speak.

This is because apraxia is a problem with planning movements, rather than the movements themselves. So even though you may not be able to say goodbye if someone asks you to, you may be able to say it when you go to leave, because you're doing it without thinking.

Signs of apraxia of speech

It can be hard sometimes to tell the difference between apraxia of speech and other communication problems.

These are some common signs:

- not being able to say words clearly, especially when someone asks you to
- your speech changes and words sound different every time you say them
- you try to correct yourself, because you know things sound wrong
- you hesitate between words, and need several attempts before you can get the right mouth shape to say a word
- you are able to say things clearly when you recite them in a list (like days of the week or numbers), but not when you're asked to say them on their own
- not being able to speak at all sometimes.

Will it get better?

Most communication problems do improve. However, how much they'll improve or how long it will take is very difficult to predict, as it's different for everyone.

Problems tend to improve quite quickly within the first three to six months, but you can continue to recover for months and even years after this. While some improvement will happen naturally, having speech and language therapy can help. Your speech and language therapist can help you work on your problems. Try to communicate with others as much as you can.

For most people, getting better is about returning to the way they were before their stroke. However, this isn't always possible. Even if you get close, you may still have problems from time to time, especially when you're tired, stressed or under the weather.

But even if you don't recover completely, there are many ways to communicate that don't rely only on speaking. Many stroke survivors continue to live full and happy lives, even though they still have problems with communication. With support, you can become more confident about communicating.

"I had a stroke eight years ago. I still get frustrated with myself when I can't get my words out, and embarrassed when I say the wrong word. But I get annoyed at other people when they think I'm OK. Not all disabilities are visible."

Clair

Are there treatments that can help?

Speech and language therapy

Speech and language therapy aims to help you improve your ability to communicate.

But speech and language therapy isn't just about 'fixing' your problems so that you can speak as well as you did before. It's not always possible to recover your speech completely, but you can develop your confidence and ability to communicate in new ways.

When you work with a speech and language therapist, what you do in your sessions will depend on the problems that you have and what's important for you to work on. You may also have therapy sessions with a rehabilitation assistant.



Setting goals

Speech and language therapy is about working towards goals and these goals need to be set by you, together with your speech and language therapist. It's no good working on your spelling, if what you really want to do is tell your family that you love them.

Working to improve speech and language

Speech and language therapy can help in a number of ways. It may work directly to improve your speech or language. The aim is to remember meanings, and be able to link them with the right words. You might try tasks such as matching words to pictures, or sorting out words by meaning. Other tasks could include naming pictures, or identifying rhyming sounds. You could practise constructing sentences, or having conversations.

Compensation strategies

While your speech and language therapy will be about getting you to speak and understand more, it will also focus on learning other ways to communicate.

A speech and language therapist can help you find ways to communicate that don't involve speaking. These are known as compensation or coping strategies. They include anything from gestures, alphabet charts and notebooks, to electronic devices: anything that helps you to get across what you want to say.

Involving friends and family

Speech and language therapy can also involve your friends and family. The therapist can work with your friends, family and carers to help them learn how to have a successful conversation with you. They can help by being encouraging. They can also take part in enjoyable communication with you to let you practice and grow your confidence.

Improve confidence

Confidence also plays an important part in your ability to communicate. Speech and language therapy helps to build your confidence, so you feel able to join in conversations, talk to new people and do the things you want to do. Meeting with other stroke survivors with communication problems can also help.

Speech and language therapy isn't just about the time you spend with your speech and language therapist. Getting better and becoming more confident only comes with practice. So the more you do outside of your sessions, the more progress you'll see within them.

Support with life after stroke

Speech and language therapists can provide information about stroke. They can often give you ideas for meeting people at local stroke groups. They can tell you where you can find more help and information.

How do I get speech and language therapy?

When you're in hospital you'll be referred to a speech and language therapist. They will assess the kinds of problems you're having. They will discuss what has happened with you and can provide you with information and support as well as therapy.

Most stroke teams include a speech and language therapist, but they can be based in other hospital departments and in the community as well, for example in an Early Supported Discharge stroke rehabilitation team.

The speech and language therapist will discuss your goals and the kind of therapy that will be best for you and set up regular sessions. This may start in hospital or when you return home.

If services are busy, and depending on the type of stroke services in your area, you may have to wait several weeks for your speech and language therapy to start once you return home. Many people find this difficult, so try to find out as much as you can while you're in hospital. Ask your speech and language therapist when your therapy will start and what you can work on while you wait.

If you don't stay in hospital, or you don't notice difficulties until you've returned home, then speak to your GP. Your GP can refer you to a speech and language therapist.

How long does it last?

There is no set length of time for speech and language therapy. Ideally, it will continue until you've achieved your goals. However, this isn't always the case. Many people find that their speech and language therapy ends before they feel ready.

Knowing that you're no longer going to have regular advice and support from your speech and language therapist can knock your confidence and make you worry that you won't improve any more than you have.

But recovery doesn't end with therapy. As you carry on practising your new skills, you'll probably see that things will get even better and your confidence will continue to improve.

"You have to teach yourself again... you have to teach yourself to talk to people."

John

What happens after speech and language therapy?

In many areas there are organisations that offer communication support such as:

- one-to-one sessions with someone who is trained to provide communication support
- communication or conversation groups where you can practise with other people
- peer-support groups such as aphasia cafés
- partner schemes that will put you in touch with someone else who has communication problems so that you can practise together.

Your speech and language therapist should talk to you about the kinds of communication support that are available to you and put you in touch with services that could help. You can do this during and after your therapy. They should also explain how you can contact them or another speech and language therapist if you need to in the future.

Depending on how confident you feel, there may be other ways to improve your communication. Many people volunteer, for example, either at their local stroke group or for another charity or organisation, or get involved in training students or stroke professionals in supported communication. This can help you become more confident about talking to new people and in different situations.

If there are still things that you want to work on, there are workbooks you can buy or websites and apps you can use to set yourself goals. These can help you break your goals down into smaller steps and record your progress as you work towards them. Ask your speech and language therapist if they can recommend some.

Why haven't I been offered speech and language therapy?

You won't be offered speech and language therapy if your speech and language therapist thinks that you won't get any benefit from it. This may be because you're too ill to take part in therapy sessions, or if your problems seem to be getting better on their own.

If you feel that you need some help with your communication, you can visit your GP. They can refer you for another assessment at any time.

"Physically and mentally and verbally, you need to just practise and practise and practise."

John

What about private therapy?

If you're not offered therapy through the NHS, or if you feel that you didn't get enough, you may want to think about private therapy.

Private therapy means finding your own speech and language therapist (SLT) and paying for treatment yourself. Prices can range between £50 and £90 for one session and initial assessments are likely to be more. So this isn't an option for everyone. If you do decide to pay for private therapy, we suggest finding an SLT who has experience of working with people who have had a stroke. Contact our Stroke Helpline if you'd like to know more about private treatment, or read our guide R10, *Private treatment*.

To find a private SLT, you can check the Association of Speech and Language Therapists in Independent Practice at www.helpwithtalking.com. Always check whether your SLT is on the Health and Care Professions Council Register at www.hpc-uk.org/check.



Are there aids or equipment that can help?

Carry a pen and notebook with you, if you want to use drawing and writing to help you communicate. The person you are speaking to can also use the notebook.

You can use a mobile phone or tablet to find pictures and words on the internet. You can get free apps for note taking and drawing on a smart phone or tablet. You can use your finger or a stylus to write and draw.

You can buy aids that can help make communication quicker and easier. They range from simple charts with words and pictures to portable electronic devices.

Because there are so many communication aids available, it's best to get advice from your speech and language therapist about which ones would be most helpful for you. Here's a brief overview of the kinds of aids that are available.

Communication cards and passports

A communication card is a card that you can use to explain to people that you have problems with speaking. It's usually small, so that you can carry it with you in your wallet or purse. A communication card can help you explain to people (like shop assistants and waiters, for example) that you need a little more time or help. We have communication cards that you can order from our website. Go to stroke.org.uk/shop.

**I have had a stroke
and find it difficult to
speak, read or write**

Please give me time to communicate.
Speak clearly, taking your time and write
down key words. Your help and patience
would be appreciated.

A communication passport is a document that tells people important information about yourself. Everything from the kind of communication problems you have and the medication you're taking, to your likes and dislikes and where you grew up. If you have problems speaking, you can use this to tell other people things they need to know about you. This can be especially helpful if you have a lot of different visitors or carers.

Anyone can make their own communication passport, although there are many templates available to help you.

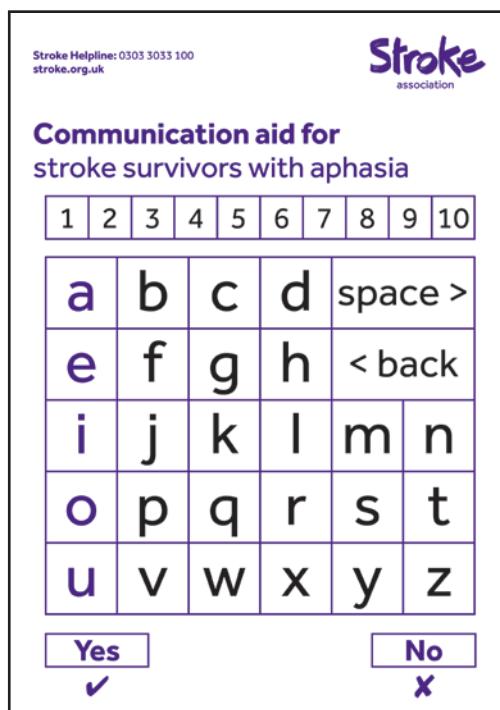


Charts and books

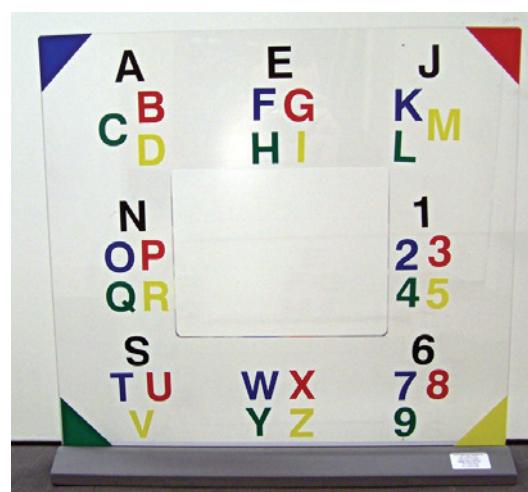
Simple communication aids include alphabet boards, communication charts and books. They display large letters or words, as well as sets of pictures, photos or symbols that you can point to. For example, many have pictures to represent feeling hungry or thirsty or being in pain.

These **communication charts** can be useful, especially in hospital, when your communication problems are likely to be worse. However, they may not be as suitable for the kind of conversations you want to have when you're back at home.

Our communication chart has been designed for people who have had a stroke. You can order it from our website. Go to stroke.org.uk/shop.



An **E-tran frame** is a special chart for people who are not able to move their hands to point. Instead, you can use your eyes to indicate a letter, word or symbol that is attached to a large frame, which is held in front of you by a trained carer.



Symbol sets are sets of picture symbols that you can use to put messages together. There are many sets available, covering a range of different topics. You can also get them in different formats, depending on what is easier for you to use.



Electronic aids

Voice output communication aids (VOCAs) are devices that can help you if you have problems speaking clearly. They use a computer-generated voice to play a message aloud. Some work by pressing a button to play a pre-recorded message, like "How are you?", whereas others have a keyboard so you can type your own message for the Voca to read aloud.



Apps and computer programmes

Apps are computer programmes that can be downloaded from the internet and used on your smartphone or tablet computer such as an iPad.

There are over a hundred apps that have been designed to help people with communication problems, but there are also many others that you may find helpful – such as apps that can set picture reminders on your phone, rather than written ones, or apps you can use to add voice recordings to the photos that you take.

Many apps are free or free to try out, but others can cost over £50. They are not always available for all devices, so it's important to do some research to find what's best for you.

The Aphasia Software Finder has information about software and apps for people with communication problems. It provides information about what the apps do, how much they cost and what devices they can be used on. The website is funded by a charity, The Tavistock Trust for Aphasia, and run by independent researchers, so all the information is impartial. Go to www.aphasiasoftwarefinder.org.

There are also computer programmes that you can use to continue practising your speech and language exercises. There are lots of different programmes that can be tailored to the things that you need to work on, whether it's speaking, writing or using numbers.

This kind of computer-based therapy works best when you have a speech and language therapist to guide you. They can make sure that you do the exercises correctly and that they're not too easy or too difficult. You may use computer programmes during the sessions you have with your speech and language therapist or they may teach you to use a computer to practise at home.

You can also buy speech and language therapy programmes yourself. There are a number of companies that sell them. However, it's a good idea to get advice from your speech and language therapist first. These programmes can be expensive, so you need to make sure that you get something suitable. Most companies will offer you a free trial of their programme before you buy it, or your speech and language therapist may be able to show you an example.

What can I do about my speaking problems?

1

Practise, practise, practise...

The more you practise your communication, the more progress you'll make. So take every opportunity you can – read things out loud, repeat the names of songs on the radio, list the days of the week in the shower, whatever you can think of. Perhaps the best thing you can do is to have enjoyable conversations with friends and family. Let them know what they can do to help the conversation go well. Perhaps it helps if they give more time to make your point? Communication is also about confidence, which will come with practice too.

2

...but know when to stop

Communication can become exhausting, especially to begin with. So it's important that you don't push yourself too hard. Listen to your body. If you're getting tired, take a rest. Find things you enjoy doing with others which don't need you to talk so much. Try listening to music, playing or watching a sport or doing gardening, for example.

3

Laugh as much as you can

It's easy to feel stupid when you're always getting words wrong. And the constant struggle to get across what you want to say can be both frustrating and exhausting. It's a lot to cope with, but for many people laughing is the best way to do it. Not only is it a good way to release tension, but it can help the person you're talking with to feel more relaxed and happy as well.

4

Be up front with people

People are more likely to give you the help and time you need if they know you've had a stroke and struggle with speaking because of it. So explain to new people. Using a communication card may help. It's not always easy to do, but you'll usually find people are much more understanding than you think they will be.

5

Get it out

Coming to terms with the effects of your stroke is difficult enough, but it can be even harder when you're not able to talk about it very well. But this shouldn't stop you from getting the emotional support you need. So if you're finding things difficult, talk to your speech and language therapist or speak to a friend or family member. You may have to arrange it so that you have the time and space you need to talk things through, but it will be worth the effort if you do. Hobbies like art, music, photography or poetry can give you a way of expressing your feelings as well.

6

Embrace technology

Smart phones and tablet computers can be useful for people with communication problems. You can use them to video chat with people, for example, which is often easier than speaking on the phone. Or you can use them to take pictures of things that you want to ask for, like your favourite foods or members of your family. If you are not at ease with technology, help is available. Try asking your speech and language therapist, or call our Helpline.

Where to get help and information

From the Stroke Association

Talk to us

Our Stroke Helpline is for anyone affected by a stroke, including family, friends and carers. The Helpline can give you information and support on any aspect of stroke.

Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100** or email info@stroke.org.uk.

Read our publications

We publish detailed information about a wide range of stroke topics including reducing your risk of a stroke and rehabilitation. Read online at stroke.org.uk or call the Helpline to ask for printed copies.

My Stroke Guide

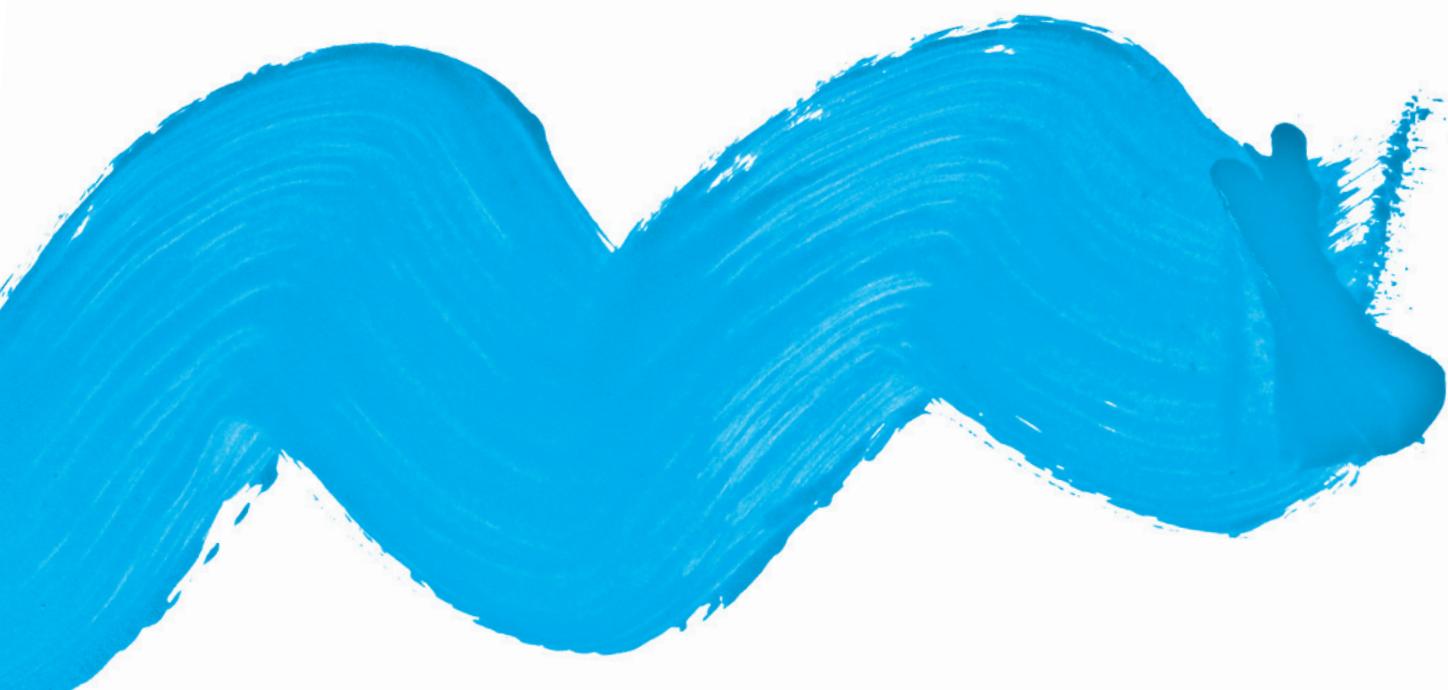
My Stroke Guide is the stroke support tool and online community from the Stroke Association. Log on at mystrokeguide.com.

Our Enquiry Line can support you with using My Stroke Guide: call **0300 222 5707** or email mystrokeguide@stroke.org.uk.

Talk to others affected by stroke

There may be a stroke group in your local area where you can meet other stroke survivors. You can meet people on our My Stroke Guide online chat forum at mystrokeguide.com, and our Facebook page Facebook.com/TheStrokeAssociation.

Call our Helpline or visit stroke.org.uk/support for more information on stroke groups and other face-to-face support.



Other sources of help and information

Aphasia Alliance

Website: www.aphasiaalliance.org

Tel: 01525 290 002

Lists organisations that people with aphasia and their carers might find useful.

Chest Heart & Stroke Scotland

Website: www.chss.org.uk

Advice Line: 0808 801 0899

Email: adviceline@chss.org.uk

A charity for people affected by chest and heart conditions as well as stroke. They offer communication support in Scotland, including groups and one-to-one support. They also have information on their website that has been written for people with communication problems.

Communication Matters

Website: www.communicationmatters.org.uk

Tel: 0845 456 8211

Email: admin@communicationmatters.org.uk

Has information about methods of communication you can use instead of writing or speaking, known as augmentative and alternative communication (AAC). Their website lists all the communication aid centres and AAC assessment services across the UK. These services can tell you about aids that can help you communicate and show you how to use them. Some also lend out equipment.



Tips for family and friends



It can be difficult to know how to help someone when they're finding communication difficult. So here are some tips to help you.



1. Get involved

If your friend or family member isn't able to communicate in the same ways as before, then you're going to need to learn new ways to do it too. Ask them what helps. Get involved with their speech and language therapy as much as you can. Go along to their speech and language therapy sessions if you're able to, or ask their speech and language therapist to send you information. Make sure you include the person in activities and conversations. Our *Guide to good conversations* later in this guide will help you.



2. Include them

Many people with communication problems say they feel invisible because people forget that they have something to say or aren't willing to put the effort in to find out. So although it can be difficult, make sure your friend or family member is included in your conversations – whether it's an argument, an important decision that needs to be made or simply a chat about the weather.

You may avoid talking to your friend or family member because you think it will make them tired or embarrassed or frustrated. But equally they might think it's because you're not interested in knowing what they have to say. So keep listening and talking. The more you practise together the more likely it is that you'll start having successful conversations.



3. Be patient

It can be distressing when someone you love can't understand what you tell them or if you can't understand them. All relationships rely on communication so it can be very hard when it suddenly becomes difficult. But things will get better with time. Even if your friend or family member never completely recovers their ability to speak, you'll find other ways to get across what you want to say to each other. It will take time and it won't always be easy, so make sure you both get the right support.



4. Don't do everything for them

Your friend or family member is going to be more reliant on you, but it won't help if you do everything for them. As their communication begins to improve, encourage them to do things on their own even if it's only small. Ask them what they'd find helpful. You may have to remind yourself to let go or give them a gentle push to try something for the first time, but remind them that you're there to help if they run into trouble.



5. Make time

People can feel very lonely and isolated when they're not able to talk or go out in the same way they used to. So simply spending some time with your friend or family member can really help. Make an effort to talk to them about how they are coping. Although it may be difficult to begin with, you'll find a way to do it. It can also help to spend time not talking as well, to give them a break. Find something you can do together that doesn't require as much chat, like cooking a meal or playing a game.

A guide to good conversations

When you're talking to someone, it's up to both of you to make sure the conversation is a good one. This doesn't change if one of you has communication problems.

It may make your conversation a bit more difficult, but it can still be enjoyable and help you to feel close.

These are our tips to help you.

Before you start

- **Make time**

Remove distractions and make sure you're not under any other pressures, so you can give each other your full attention.

- **Focus on what you're doing**

Look as if you're ready to talk, sit close to or opposite each other and make eye contact.

- **Don't worry**

Conversations are about sharing and understanding each other, so it doesn't matter how you do it or how long it takes. Be ready to make mistakes; you just have to keep trying.

- **Get ready to listen**

The best conversations involve everybody equally, so good communication is as much about listening as it is talking.

To be a good listener you need to:

- give time and attention
- try not to interrupt
- allow silences
- ask questions
- give feedback
- check you've understood.

During your conversation

Do

- Keep it simple. Keep sentences short and ask one question at a time.
- Say when you don't understand. It's not a problem, you just need to try it again. It can help to repeat back the part of the message you have understood.
- Stick to one topic at a time and make sure you both know when you've moved on to a new one. If the conversation breaks down, it's can be helpful to check you're talking about the same topic.
- Use whatever you can: point to things, make gestures, write, draw, hum or sing. Ask them what they find helpful.
- Talk naturally about things that are of interest to each other.
- Remember that conversation is more difficult if you are somewhere noisy or full of distractions.

Don't

- **Rush:** give each other time to understand and respond.
- **Finish sentences or guess** what the other person is trying to say. It's extremely frustrating. Just give them the time they need to get there themselves.
- **Ask questions you already know the answers to.** It's a conversation, not a test.
- **Pretend to understand** what they've told you or assume that you have: always check.
- **Forget that you're talking to an adult** who has problems with their communication, not their intelligence.

Some other things to think about

- Check yes/no responses. Sometimes people with aphasia say yes or no when it's not what they mean. So check with a simple thumbs up or thumbs down, or draw a tick and a cross on a piece of paper and ask them to point.
- Write down key words. Even if they can't read very well, many people can still recognise single words. So writing down key words as you go along can help you if you run into trouble.
- If your conversation partner is struggling to think of a word, then ask them to spell it, write it down, or point to what it begins with on an alphabet chart.
- Think about other things that you can use to help your conversation. Do you have pictures from your holiday you're talking about, which you could look at while you chat? Or why not sit down with a photo album or a newspaper, or perhaps a book on a topic that interests one of you, and talk about that together?
- Ask them what they find helpful. Also let them know what helps you in the conversation.

Five rules of good conversations

1. show respect
2. give each other time
3. listen
4. show you are concerned and care about them
5. never assume.



About our information

We want to provide the best information for people affected by stroke. That's why we ask stroke survivors and their families, as well as medical experts, to help us put our publications together.



How did we do?

To tell us what you think of this guide, or to request a list of the sources we used to create it, email us at feedback@stroke.org.uk.



Accessible formats

Visit our website if you need this information in audio, large print or braille.



Always get individual advice

Please be aware that this information is not intended as a substitute for specialist professional advice tailored to your situation. We strive to ensure that the content we provide is accurate and up-to-date, but information can change over time. So far as is permitted by law, the Stroke Association does not accept any liability in relation to the use of the information in this publication, or any third-party information or websites included or referred to.



Your notes

Contact us

We're here for you. Contact us for expert information and support by phone, email and online.

Stroke Helpline: 0303 3033 100

From a textphone: 18001 0303 3033 100

Email: info@stroke.org.uk

Website: stroke.org.uk

We are the Stroke Association

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research to develop new treatments and ways of preventing stroke.

We rely on your support to fund life-saving research and vital services for people affected by stroke. Join the fight against stroke now at stroke.org.uk/fundraising.

Together we can conquer stroke

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