

# My Stroke Journey

A book for stroke survivors, families and carers



**Keep this with you from hospital to home**

# About the Stroke Foundation

The Stroke Foundation is a national charity that partners with the community to prevent, treat and beat stroke. We stand alongside stroke survivors and their families, healthcare professionals and researchers. We build community awareness and foster new thinking and innovative treatments.

We support survivors on their journey to live the best possible life after stroke. We are the voice of stroke in Australia and we work to:

- › Raise awareness of the risk factors, signs of stroke and promote healthy lifestyles.
- › Improve treatment for stroke to save lives and reduce disability.
- › Improve life after stroke for survivors.

- › Encourage and facilitate stroke research.
- › Advocate for initiatives to prevent, treat and beat stroke.
- › Raise funds from the community, corporate sector and government to continue our mission.

Visit [strokefoundation.org.au](https://strokefoundation.org.au) for more information.

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# About this book

Most people don't know much about stroke until they or someone they know has one. My Stroke Journey will give you the information you need. Keep this book with you – it belongs to you.

## How to use this book

My Stroke Journey answers these questions:

- › What is a stroke?
- › How will my stroke affect me?
- › How do I take care of my health after my stroke?
- › What happens when it's time to leave hospital?

Stories from stroke survivors and families give you an idea of the road ahead. There are pages in the book for you and your family to write notes. The Strokesaurus at the end of the book explains medical terms.

You don't need to read My Stroke Journey from cover to cover. Use the Contents page to find the information you need when you need it.

## Working with your stroke team

Your stroke team will use My Stroke Journey to share information with you about your stroke. They will also use it to develop your care plan.

The My Care Plan pages are blue along the top or side of the page. These pages are for recording information about your stroke, your health and your plan to leave hospital.

## For family and carers

This book has sections labelled *For family and carers*. These are for anyone providing support and care to the stroke survivor.

If family, carers or friends would like a copy of My Stroke Journey:

- › Print one from our website – visit [strokefoundation.org.au](http://strokefoundation.org.au)
- › Call StrokeLine on 1800 787 653 and we will post them one.



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# 1. What is a stroke?

Stroke happens in the brain.

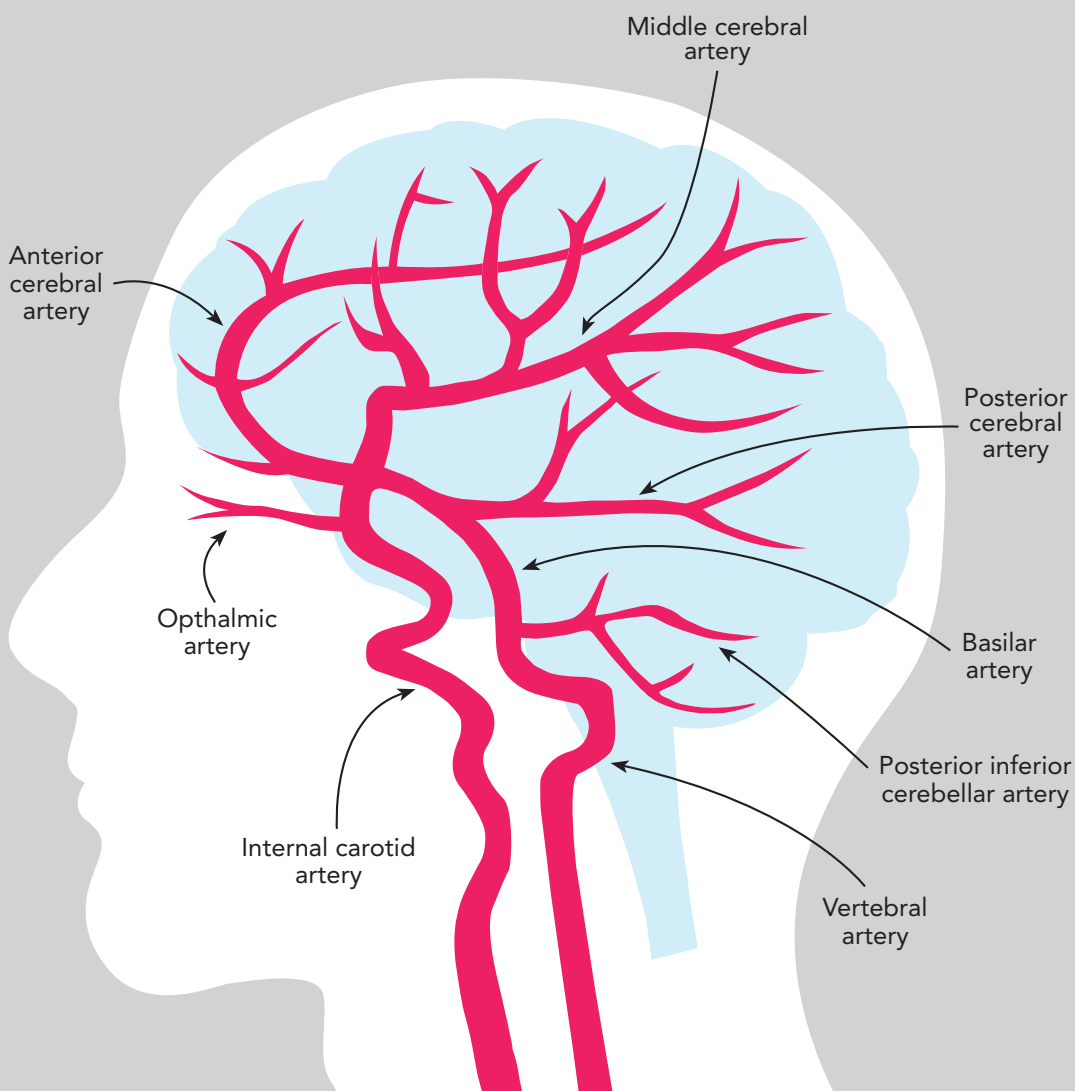
A stroke is when there is a problem with the blood supply to the brain. Blood is carried through your brain by blood vessels called arteries.

Blood carries oxygen and nutrients for your brain cells. If the blood supply stops, your brain cells start dying.

Some brain cells can last a few hours if the blood supply is not cut off completely. If the blood supply returns in the hours immediately after the stroke some of these cells may recover.

If the blood supply does not return, the affected part of your brain will be injured.

## Arteries carry blood through your brain.



## Types of stroke

### Ischaemic stroke

A stroke can be caused by the artery being blocked by a blood clot. This is called an ischaemic stroke. It's pronounced is-key-mick.

A blood clot can form in the heart or blood vessels in the neck and travels through the bloodstream to the brain. It gets stuck in an artery too small for it to pass through, stopping the blood supply.

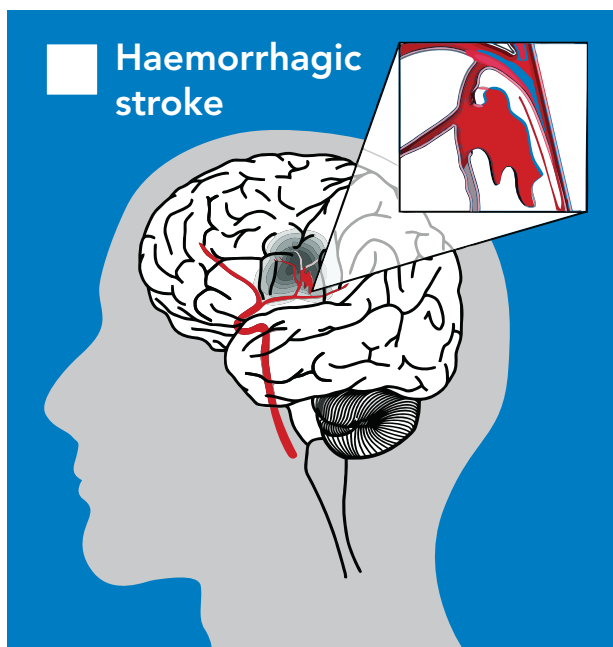
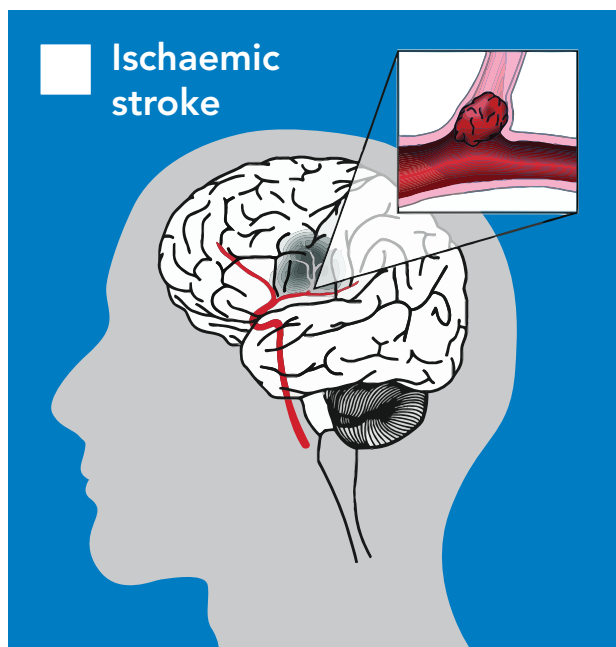
Cholesterol plaque can form in the wall of the arteries. These plaques can narrow the artery. A blood clot can form on the plaque and block the artery in the neck or travel up to the brain, stopping the blood supply.

### Haemorrhagic stroke

A stroke can be caused by bleeding if an artery breaks or bursts. Blood leaks into the brain like a bruise, injuring that area of brain. This is called an haemorrhagic stroke. There are two types of haemorrhagic stroke:

- › Intracerebral haemorrhage is bleeding within the brain itself. Most intracerebral haemorrhage is caused when a very small blood vessel in the brain bursts.
- › Subarachnoid haemorrhage is bleeding under the membrane surrounding the brain, usually because of a burst aneurysm. An aneurysm is a weak or thin spot on an artery wall.

### My stroke:



### Other details:

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## Tests

At the hospital, your doctors and nurses will assess your symptoms and do tests to confirm you have had a stroke. They will do tests to find out:

- › What type of stroke you had.
- › What area of your brain is injured and how badly.
- › What caused the stroke.

After a stroke, everyone will need a different set of tests. Some tests will be done while you are in hospital. Others may be done after you go home.

### Brain scans and tests

**Computerised tomography (CT) and magnetic resonance imaging (MRI).** Scans take pictures of your brain to show areas of injury and swelling. After a stroke a CT or MRI should be done urgently. These scans confirm you have had a stroke and the type of stroke you had.

**Cerebral angiogram.** A small tube called a catheter is inserted through an artery in the arm or leg and fed into the brain. A dye is injected through the tube and X-ray images are taken. The images show how dye moves through the arteries and veins of the brain. Doctors can see if there is a problem with the blood supply to the brain and where the problem is.

**Carotid Doppler ultrasound.** The carotid arteries in the neck carry blood to the brain. An ultrasound of the neck arteries show if these are narrow or partly blocked.

### Heart tests

Your heart pumps blood to your brain, so problems with your heart can cause a stroke. Heart tests include:

**Electrocardiogram (ECG).** Electrodes placed on the skin of the chest record the electrical activity of the heart. This test for abnormal heart rhythm or heart disease is recommended for everyone after a stroke.

**Holter monitor (ECG).** A wearable device measures your heart activity continuously over a longer period of time, usually 24–48 hours.

**Echocardiogram (Echo).** Ultrasound to look at the structure and function of the heart. An Echo can show if there is a blood clot in the heart, if the chambers of the heart are enlarged or the valves are not working properly.

**Transoesophageal echocardiogram (TOE).** A tube-like device is passed down the throat into the oesophagus. This test gets a clearer view of the heart muscles, valves and area around the heart.

### Blood tests

Blood tests can help diagnose health problems that may have caused your stroke. The most common tests measure:

- › The time it takes your blood to clot (your International Normalised Ratio or INR).
- › Kidney function.
- › Blood sugar levels.
- › Salt levels.
- › White blood cell count.
- › Cholesterol levels.
- › Iron levels.



## Swallowing test

A stroke can affect how you swallow. If food, drink or medication go down the wrong way and get into your lungs it can cause an infection. After a stroke, everyone should have a swallowing test before being given anything by mouth.

## Treatment

Treatment cannot repair injury to the brain. Instead, treatment is given to minimise the injury to the brain.

### Treatment for ischaemic stroke

Early treatments for ischaemic stroke are called reperfusion therapies. The aim is to dissolve or remove the clot, returning the blood supply to the brain.

Before any treatment, a brain scan is done to confirm it is an ischaemic stroke.

These treatments are time-critical. The sooner the blood supply can be returned, the greater the benefit.

As with all medical treatment, there are risks. The risks increase as time passes, so treatment is only recommended within specific timeframes.

Treatment is not appropriate for everyone. Your doctor will decide whether treatment is appropriate for you and will discuss their recommendation with you or with the person making the decision for you.

These treatments are not performed at all hospitals so you may need to be transferred to another hospital.

**Thrombolysis** is when a drug is given to dissolve the clot. It is given as an intravenous injection in your arm. Thrombolysis should be given as early as possible, generally within 4.5 hours of the stroke starting.

**Endovascular clot retrieval (ECR)** is the physical removal of a clot from a large artery. A small tube called a catheter is inserted into an artery in the groin or arm and moved up into the brain arteries. A suction device or metal net called a stent is used to capture and remove the blood clot that is blocking the artery and causing a stroke. Also called thrombectomy.

## Other treatment

**Aspirin or other blood thinning medication** is given in hospital to people who have had an ischaemic stroke to reduce the risk of another stroke. If you haven't had thrombolysis it's given within the first 24 hours. If you have had thrombolysis it's given **after** the first 24 hours.

**Carotid endarterectomy** is a surgical treatment for severe but not total blockage of the carotid arteries. The carotid arteries carry blood to the brain.

A carotid endarterectomy removes the plaque blocking the arteries. This improves the blood flow and lowers your risk of another stroke.

## Treatment for haemorrhagic stroke

Treatment focuses on controlling the bleeding in your brain and reducing the pressure caused by the bleeding.

Drugs can be used to reduce blood pressure to reduce the risk of ongoing bleeding.

Surgery may be needed to repair the damaged artery and stop the bleeding. Surgery may also be required to relieve the pressure caused by the build up of blood.

Surgery may be needed to seal or remove:

- › A weak or thin spot on an artery wall (an aneurysm).
- › A tangled mass of arteries and veins (an arteriovenous malformation or AVM).



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Endovascular Clot Retrieval captures and removes the blood clot causing the stroke.







## Tony's story

It was the last thing on my mind, that I'd have a stroke. I was reasonably fit, although I did have an underlying blood condition that increased my risk of stroke. I hate to think of the trauma for my wife, my two girls, my friends and family, looking at me fully paralysed in the intensive care unit. I was very fortunate – that unit saved my life and the staff at rehab gave me that life back.

When I arrived at rehab my muscles were so weak I couldn't hold my head up. Rehab taught me how to walk and move through thousands of repetition exercises. It's the start of a long journey.

Everyone has a different stroke. Everyday I'm a bit better. My vision probably won't improve but I'm still working on my hand function. If anyone was asking how to cope with life after a stroke then I'd say to focus on the things you do well.

The old Tony could stop locomotives and jump tall buildings. The new Tony is a new and exciting guy that I'm very surprised that I have found. Without the stroke I'd still be doing the same routines. Since my stroke, I've become a public speaker and a fundraiser, and I've written six books about the bus industry, of which I've been a respected member for 40 years. So whilst you feel that you have been struck a devastating blow, there is a new person that you can find.

### Tony, stroke survivor

## Your stroke team

After a stroke, everyone should be admitted to hospital and be treated in a stroke unit.

Stroke unit care is care by a group of doctors, nurses and allied health professionals who specialise in stroke. Everyone should be given stroke unit care. Stroke unit care has been shown to improve recovery after stroke. Not all hospitals have stroke units so you may be transferred to a hospital with a stroke unit.

Every hospital and team is organised differently. The list below explains team member's roles. Your team may not have all the members listed. In some teams, people's roles may be slightly different.

### Doctors

Doctors assess your health and diagnose and treat illness. They manage your medical care.

**Consultant.** Leads your medical care. Your consultant is a specialist doctor – most likely a neurologist, rehabilitation physician or a geriatrician. The consultant attends ward rounds and meetings at specific times.

**Registrar.** Based on the stroke unit and the unit's senior doctor. The registrar has specialist training.

**Resident.** Looks after patients on the stroke unit and is typically the doctor you will see most often.

**Interns.** Have completed their medical degree and are in their first year of working in the hospital.

### Nurses

Nurses observe and assess your health, communicate with your doctors and manage your daily treatment and care.

**Nurse unit manager (NUM).** Runs the ward, assisted by associate nurse unit managers (ANUM).

**Clinical nurse consultant (CNC).** Highly trained nurse in a specialist area like stroke.

**Registered nurse.** Observes and monitors patient health, gives medication and performs minor procedures.

**Enrolled nurse.** Provides general nursing care.

## Allied health

Allied health professionals manage the effects of your stroke, plan your rehabilitation and help you make progress with your recovery.

**Dietitian.** Assesses your dietary needs and arranges a special diet if needed. Gives advice on diet to improve your health and reduce your risk of having another stroke.

**Neuropsychologist.** Provides assessment and therapy to help manage the effects of stroke on concentration, memory, judgement, mood and behaviour.

**Occupational therapist (OT).** Assesses your physical abilities, along with your thinking and memory. Helps you get back to doing day-to-day tasks such as getting dressed or making meals. Provides advice on parenting, driving and work. May visit you at home to assess your needs and see if you need equipment or modifications.

**Physiotherapist.** Assesses how you sit, stand, walk and exercise. They focus on movement, muscle strength, sensation, coordination and fitness. They work with you to develop an exercise program to meet your needs. Assesses your risk of falling and works with you to reduce your risk, including advising on mobility aids such as walking sticks and frames.

**Psychologist.** Provides assessment and therapy for your mental health, including managing depression and anxiety.

**Social worker.** Helps with the emotional, social and practical impacts of your stroke. Provides information on financial issues, government payments and legal issues such as decision making. They help with planning for life after hospital, particularly when you need new services or accommodation.

**Speech pathologist.** Assesses your swallowing. Recommends a modified diet and helps with exercises to improve your swallowing. May assess your communication – your ability to speak, understand, read and write. Can work with you on an exercise and practice program, and help with communication aids and strategies.

## Other people who may be a part of your stroke team

**Allied health assistants (AHA).** Working under the supervision of allied health professionals, an AHA may help you to do your exercises and to practise tasks.

**Pharmacist.** Provides information on the medication you are taking and its possible side effects. Provides advice on lowering your risk of having another stroke, including help to quit smoking. Gives you a list of all

your medications when you leave hospital. Makes sure you have enough medication to last until you visit your general practitioner (GP) or specialist.

**Stroke care coordinator, discharge planner or key worker.** Some teams also have people who assess your overall needs and make sure the right members of the stroke team are involved in your treatment. They provide information and plan your care, including arranging rehabilitation. They lead planning for your discharge from hospital.





## My stroke team

Name	Contact details
Consultant	
Registrar	
Resident	
Nurse unit manager	
Stroke care coordinator	
Neuropsychologist	
Occupational therapist	
Physiotherapist	
Psychologist	
Social worker	
Speech pathologist	
Pharmacist	
Stroke care coordinator, discharge planner or key worker	

## 2. How will my stroke affect me?

Our brain controls everything we think, feel, say and do.

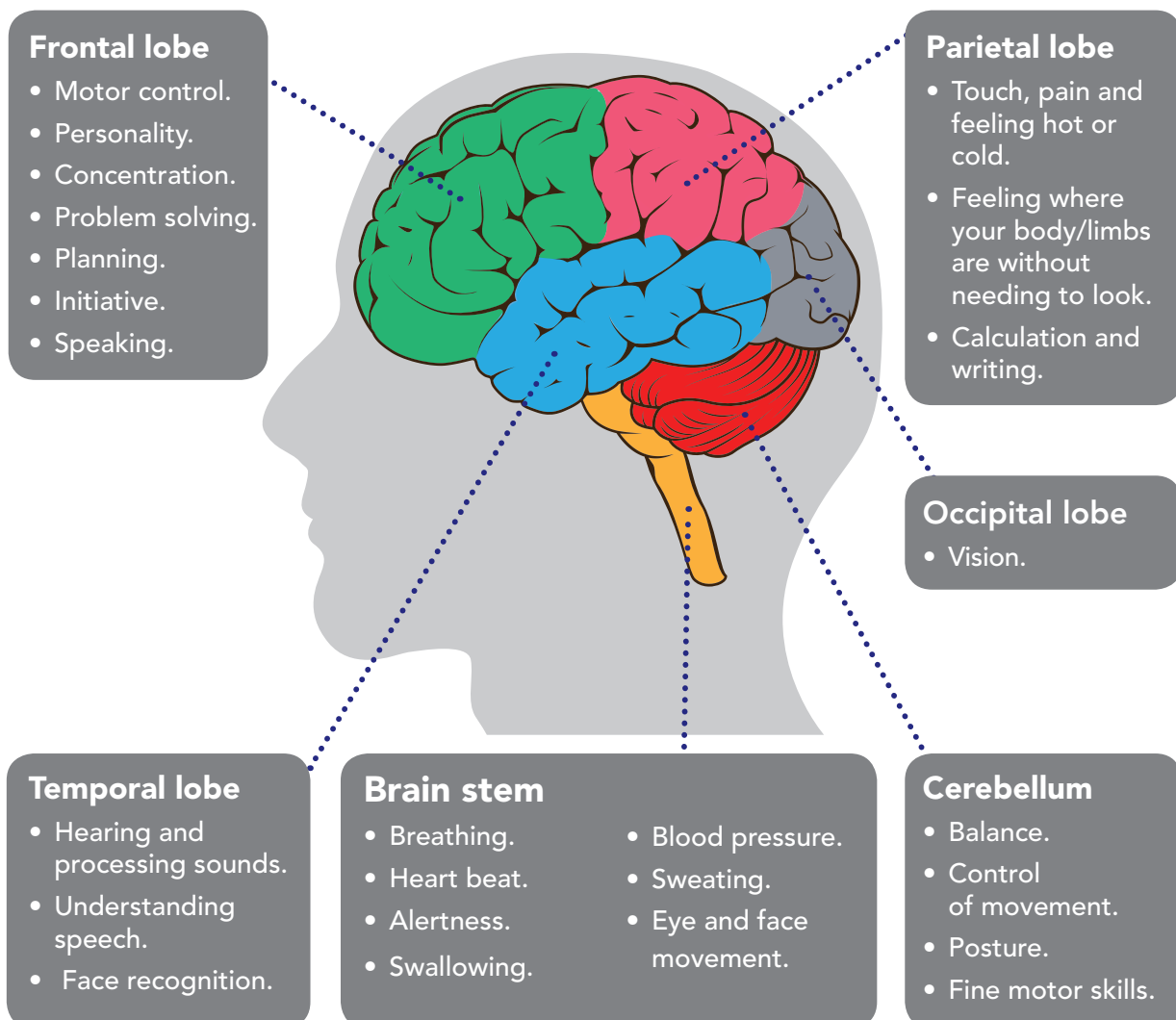
The brain has two sides: the right and left hemispheres. The right hemisphere controls most functions on the left side of the body. The left hemisphere controls most functions on the right side of the body.

Each side of the brain is divided into areas called lobes. Each lobe controls different things.

Everyone's stroke is different. How your stroke affects you depends on the area of your brain that is injured and how badly.

Keep in mind most people improve with time and rehabilitation.

### Areas of the brain



## Effects of stroke

### Moving and walking

Stroke can affect your ability to sit, stand, balance, walk and move.

Moving and walking may be difficult because:

- › One side of your body is weak or doesn't move at all.
- › You can't plan or coordinate movement.
- › Your muscles are stiff and tight, or floppy and loose.
- › You feel off balance, unsteady or dizzy.

Changes to your hand, arm and shoulder (your upper limb) are common after stroke. Weakness, stiffness, looseness or trouble coordinating movement can all affect your upper limb.

### Communication

Stroke can affect your ability to speak, understand, read or write.

When these difficulties are caused by injury to the language area of the brain, it's called aphasia. You may find:

- › It's hard to think of the right word.
- › You use the wrong word or sound.
- › You don't understand what someone is saying.
- › Words on a page don't make sense.

Other issues can affect communication too. Sometimes after a stroke the muscles you use to speak are weak or don't work at all. It can also be difficult to plan and coordinate movement of these muscles. This makes your speech slurred or changes your voice, making it difficult to understand you.

### Thinking, memory and judgement

Stroke can affect your thinking, memory and judgement. This is called cognition.

Changes to your cognition make it hard to:

- › Pay attention and not get distracted.
- › Plan how to do something.
- › Do things in the right order.
- › Understand and fix a problem.

Problems with your short-term memory mean you don't remember things that happened a short time ago.

Problems with judgement mean you have difficulty making good decisions. Some things you do may make you unsafe.

## Claire's story

Imagine waking up and finding you can't utter one word. A few weeks after the stroke I managed to say "hello". Finding the word I wanted to say was challenging enough, but working out how to pronounce it was even more testing. When I did manage to speak the words, the ones in my head were often different from those I was verbalising. I couldn't trust what I was saying.

I made good progress to begin with. Before long I could get by, despite some mistakes, however I became self-conscious and fearful. I retreated, speaking less and less until I felt like a mouse in the corner with nothing to say. As my confidence diminished, my life became smaller until I felt as if I was locked in a world of my own. Nothing was tremendous or amazing, at best it was just 'good'. I had lost all my confidence and enthusiasm, and no-one knew how I felt.

I realised I had to move out of my comfort zone. This meant being vulnerable, embarrassed, as well as being afraid and scared of what people might think, say or do.

I continued to push the boundaries. I found increasing my vocabulary improved my imagination, my thinking and how I felt which changed and expanded my world.

The negative monkey chatter in my head impeded my recovery. Words have an energy associated with them such as 'should', 'try' and 'hard'. 'Should' has the energy of guilt; using words like 'could' or 'would' proffered me possibilities. It's better to use a definite 'will' or 'won't'. You don't just 'try' to do something; you either do it or you don't. 'Hard' is immovable, like concrete; I prefer the word 'challenging', as this suggests the chance of achieving something. Using more positive words empowered and propelled me forward.

My speech is mostly automatic, although I still have my moments when I have to pause and search for words, or ponder how to pronounce them. Best of all, I have gained the confidence to speak in public.

**Claire, stroke survivor**



## Personality and behaviour

Stroke can affect your personality. Some personality traits can become much stronger. People can also behave in ways out of character for them.

Personality changes after a stroke can include:

- › Not feeling like doing anything.
- › Being irritable, aggressive or lashing out.
- › Acting without thinking.
- › Saying or doing things that are not expected or usual.

## Vision and senses

Stroke can affect how well you can see. It can also affect how you sense and perceive things.

**Vision.** You may have visual field loss. This is like a blind spot only bigger – it's like people and things in the missing part of your vision aren't there.

You may have blurred or double vision. You can also have problems controlling eye movement. Your eyes may be more sensitive to light.

**Senses.** Your ability to feel touch, pain or temperature can change. Your sense of taste and smell may change. You may have numbness or pins and needles. You may not be aware of where parts of your body are or how they're moving.

After a stroke, you may be overwhelmed by busy, noisy environments. Our brains identify and filter out unnecessary sensory information.

When your brain has difficulty doing this it can make you feel overwhelmed and confused. This is called sensory overload.

**Perception.** You may not recognise objects or even parts of your body. You may ignore people and things on the side of your body affected by your stroke.

## Other affects

**Swallowing.** Stroke can affect the muscles you use to move food around in your mouth and how well you can swallow. This creates difficulties swallowing food, drink or even your own saliva. Food or drink can go down the wrong way and get into your lungs, causing an infection.

**Appetite.** Physical, cognitive, emotional and sensory changes can mean you don't have much of an appetite after your stroke.

**Incontinence.** Incontinence is being unable to control your bladder or bowel – having 'accidents'. You might not know when you need to go to the toilet, be unable to get there in time or ask for help.

**Pain.** After a stroke you may feel pain from changes to your body. Stiff or tight muscles are a common reason for pain.

Pain can also be caused by damage to the brain's pain-processing pathways. This is called central post-stroke pain (CPSP) or nerve pain. You experience pain even though there is no actual injury or problem in your body. You may also have headaches.

## Emotions and mood

**Emotional reactions.** It's very normal to experience strong emotions after a stroke. You may feel anxious about why you had a stroke and whether you will recover. You may be angry it happened to you. You might feel grief or sadness at the change from how you were before. You may feel gratitude at survival, hope about your recovery and love for family and friends.

**Emotional lability.** This is when your emotional responses don't make sense or are out of proportion. You may cry or laugh uncontrollably. Your emotional responses may not make sense for the situation you are in.

## Depression and anxiety

Depression and anxiety are common after a stroke. You may have depression if you feel sad or down for more than two weeks. You may lose interest in things you normally enjoy, lack energy, have difficulty sleeping, or sleep more than usual. You may find it difficult to concentrate, to solve problems and to keep appointments.

You may have anxiety if anxious feelings do not go away once a stressful situation is over, or if you are anxious for no particular reason.

Depression is most common in the first year after a stroke, however it can happen at any time. The more severe your stroke, the more you are at risk. Having difficulty communicating after your stroke puts you at higher risk.

Never ignore the signs of depression or anxiety. Depression and anxiety are highly treatable and recovery is common. Speak to your doctor or other stroke team member.

## Fatigue

Fatigue is very common after stroke. It is a feeling of weariness, tiredness or a lack of energy. Fatigue after stroke is not improved by rest, so it is not like typical tiredness.

It can be physical, cognitive or both. Cognitive fatigue is often described as 'brain fog'.

Fatigue may make the effects of your stroke worse. For example, it may be harder to think of the right word.

Fatigue can affect anyone, no matter how mild or severe their stroke. It is most likely to start in the first weeks after a stroke but for some people it can start months later. For many people it does improve with time, however it is unpredictable and can last longer than you expect.

## Sex and relationships

Stroke can affect how your body feels and works and how you feel about yourself. It can also affect your relationship with your partner.

## My fact sheets – effects of stroke

Read our fact sheets to learn more about:

- › The reasons behind the effects of your stroke.
- › What you can do to improve or manage them.
- › Helpful services.

Your stroke team can give you copies.

You can also:

- › Visit [strokefoundation.org.au](http://strokefoundation.org.au)
- › Call StrokeLine on **1800 787 653**.

Tick box	Effect	Fact sheet	Who can I ask about this?
	Appetite	Diet	Dietitian
	Communicating	Communication	Speech pathologist
	Moving and walking	Mobility and exercise Muscle spasticity Upper limb	Physiotherapist Occupational therapist
	Emotions	Depression and anxiety Emotional and personality changes	Social worker Psychologist
	Fatigue	Fatigue	Occupational therapist Physiotherapist
	Incontinence	Incontinence	Nurse Occupational therapist
	Pain	Pain	Doctor Occupational therapist Physiotherapist
	Personality and behaviour	Emotional and personality changes	Occupational therapist Neuropsychologist Psychologist Social worker
	Sex and relationships	Sex and relationships	Doctor Occupational therapist Physiotherapist Social worker
	Swallowing	Swallowing	Speech pathologist
	Thinking, memory and judgement	Thinking and perception	Occupational therapist Neuropsychologist
	Vision and senses	Vision	Occupational therapist Ophthalmologist or orthoptist



# Neuroplasticity

## Neuroplasticity

Neuroplasticity is your brain's ability to change. This can happen in two ways:

1. The damaged area of the brain may repair itself and start working again. This can sometimes happen naturally in the early stages of stroke recovery. Doing tasks that the damaged area is responsible for can also help.
2. Other parts of the brain can take over the tasks the injured area used to do. This can happen when the injured area can't be repaired. However, a lot of effort is needed to 'rewire' the brain.

Practice and repetition of tasks is vital. It may take many repetitions of a movement or task over several days or weeks before you see improvement.

Neuroplasticity is happening as you work on your rehabilitation and recovery. People can continue to improve for years after their stroke if they can keep practicing.

## Predicting improvement

A very common question at this time is 'How much will I improve?'

Your team can provide an indication of how much they think you will improve. Factors your team will consider include:

- › The area of your brain that was injured and how badly.
- › The effect of any treatment you received.
- › How you respond to therapy – exercising and practising.

It's still difficult to be definite about what will happen. Your stroke team may instead talk about what is likely to happen.

There are lots of different factors that influence recovery and there are some unknowns too. Just like everyone's stroke is different, everyone's recovery is too.

Not knowing how much you will improve is hard and it can be difficult to make plans. Setting goals and taking steps to achieve them will help. Talk to a member of your stroke team and to your family and friends about how you are feeling.





## Emma's story

I felt extremely lost after my stroke – I couldn't go backwards to my old life but there was nothing to go forward to. Despite being physically impacted by my stroke, over time the emotional toll became quite evident. I realised the importance of focusing on my physical and emotional obstacles to ensure my optimal recovery.

It was especially hard for me hearing people say "Oh I saw a glimpse of the old Em" because I knew she was gone. We all had to accept that as difficult as it was, she wasn't going to come back.

It wasn't until I started to do new things, things that highlighted my strengths and not my weaknesses, that I found the "new Em". I had a new direction.

For me it was about being open to different opportunities. There's not one thing I do the same way as before, but I still live by my values, by what matters to me. So although I can no longer run, I can still fulfill my value of health and well-being by swimming instead.

Being with my friends is very important. Most of my friends had never been around someone who had survived a stroke. I needed to tell them it was okay for them to open up to me. I found it was my role to make it easier for them – I wanted to help them grieve too.

It's not what happens to you that matters, it's how you choose to deal with it.

**Emma, stroke survivor**

## Rehabilitation

Rehabilitation is where you relearn how to do things, practising and repeating them many times. You may also learn different ways to do things, taking account of how your stroke affected you.

Your stroke team will assess how your stroke has affected you. They will begin therapy with you – exercising and practising. This starts as soon as you are well enough.

Every activity is an opportunity for rehabilitation. Bathing, brushing teeth, getting dressed, moving from place to place and eating and drinking can all be a part of it.

After the need for acute care has passed, everyone should be offered an assessment for rehabilitation services. The only exceptions to this are:

- › People who have made a complete recovery.
- › People who are very unwell – in a coma or receiving palliative care.

When deciding if you are suitable for rehabilitation, your stroke team will consider if you are able to:

- › Improve enough to make a difference to your daily life.
- › Cope with the demands of rehabilitation.
- › Work with the rehabilitation team to set and reach your goals.

The amount and type of therapy you receive depends on the effect of your stroke and your individual needs and goals.

There are three types of rehabilitation locations:

- › **Inpatient rehabilitation** at a hospital.
- › **In-home rehabilitation** – your team provides therapy in your home.
- › **Community or outpatient rehabilitation** – you visit a centre or hospital for therapy while living at home.

If you have private health insurance, you can be assessed by a team from a private rehabilitation hospital. Ask your stroke team about this. Learn as much as you can about the type and amount of therapy offered by the different providers so you can make the best decision.

Another important part of rehabilitation is learning how you will continue your recovery once you are back at home. Be sure to ask your rehabilitation team about this, especially as you get closer to leaving hospital.

## Tips for making the most of rehabilitation

**Set goals.** After a stroke it can be difficult to see a path from where you are now to where you want to be. Setting goals can help you and your team:

- › Focus on what's most important to you.
- › Break things down into steps.
- › Make a plan and follow it.
- › Track your progress.

Here are some tips on setting goals:

**Pick an area you want to improve on.** Ask yourself 'What is it I can't do now that I really want to do?'

**Be specific.** Focus on a specific task like getting dressed independently or walking a particular distance.

**Break it down.** Your team can help with planning out the steps to reach your goal.

**Celebrate success.** Don't forget to stop and enjoy completing a step or reaching your goal. Keep a diary, take a photo or make a video to remember the moment.

Your rehabilitation team may have a process and a tool they use to set goals with you. You can also make a start on the next page.

Other ideas for making the most of rehabilitation include:

**Keep exercising and practising.** Ask your rehabilitation team about what you can do outside of therapy time.

**Recruit visitors.** Spend some time catching up, and then ask people to spend time helping you exercise and practise. Show them what you're working on in therapy and get them involved. Your rehabilitation team can help with ideas.

**Balance activity and rest.** Rehabilitation is hard work. Remember to take breaks and try to get good quality rest and sleep. Practise and exercise outside of therapy time can be done in short bursts. Remember, recovery is a marathon not a sprint.

**Plateaus are part of the process.** Your recovery may slow down or seem to stop for a time. Treat a plateau as a chance to reassess, not an end to recovery. Talk with your team and make a plan to keep working.

**Share how you are feeling.** You will have tough times. It's completely normal. It's impossible to be positive all the time. Be open about this – talk to your team and to a trusted family member or friend.

## Paul's story

In the early stages of my rehab, I struggled with goal setting. I thought it was obvious... my goal was to be normal. I soon realised I needed to break it down into smaller goals.

Having a family gave me my motivation and direction for rehab. My biggest goals were always centred around my son and my family. An important part of therapy is not only learning new skills but actually using them in real-life situations. Basically I was trying to contribute to my family life.

My therapists and my wife were amazing at helping me to set goals around my time with my son. One big goal was improving my speaking, writing, reading and understanding. My speech therapists helped pick out the best books for me to read out loud with my son. They needed to be appropriate for him, achievable for me and challenging enough so I could keep improving. I would practice my speech with my son and the more I said funny-sounding words or made mistakes the more he laughed.

My physiotherapists helped me to walk unaided, so I had a free hand to play with him. They also taught me how to get on and off the floor so that I could comfortably play with him on his level.

My occupational therapists taught me how to prepare foods that my son liked, get him dressed, change his nappies.

All this helped me to achieve my goal of being able to independently look after my son.

Coming home from the hospital allowed me to brainstorm meaningful goals. I wanted to be more useful around the house and I wanted to achieve more independence. I needed to make practice something I could do across the whole day in all sorts of activities, not just while I was in therapy sessions.

I started to challenge myself to use my affected arm and hand to do things like water the garden and hang up washing. I even used cleaning up my son's toys as a way to re-educate my right hand to start working. I would aim to pick up the toys, and then move my arm to place them in the bucket. I still empty the dishwasher with my affected hand. As I place the utensils in the drawer, I practice my speech by saying out loud what they are: knife, fork, spoon.

Achieving smaller goals in my structured rehab meant I could set myself goals to do the things I love. I wanted to get back to reading, walking, swimming and the gym. Whilst I don't look or sound like my 'normal' self, I have started participating in normal activities. That makes me feel happy and satisfied with my achievements so far.

**Paul, stroke survivor**





## My goals

Talk to your stroke team about how they will help you set and achieve your goals.

You can write your goals down here. Break your goal down into steps. Think about how long it will take.

Learn more about goal setting by visiting our stroke recovery website, [enableme.org.au](http://enableme.org.au)

You can set goals, make a plan and track your progress.

### After you go home

Our StrokeLine team can help you with goals. Call **1800 787 653**.

<b>Goal:</b>
<b>Steps:</b>
<b>I want to achieve this goal by:</b>

<b>Goal:</b>
<b>Steps:</b>
<b>I want to achieve this goal by:</b>

<b>Goal:</b>
<b>Steps:</b>
<b>I want to achieve this goal by:</b>



# enable *me*

stronger after stroke

EnableMe is a website for stroke survivors and families. EnableMe can help with your stroke recovery.

## Accessibility settings

EnableMe can change to suit you. Choose easy English to make it easier to read. Choose a larger text size, high contrast or align the text on the screen to suit you. You can also have the text read out loud to you.

## Information

Information on every aspect of stroke recovery. Get fact sheets, listen to podcasts and watch videos. Find helpful products and services.

## Community

Meet others, ask questions and find support. Tell your story or start a conversation about what matters to you. Hear from others who have been through stroke and stroke recovery.

## Ask a health professional

Ask Stroke Foundation health professionals questions and get the answers you need.

## Strokesaurus

A complete A to Z guide of medical terms. It's also available in Easy English to make it easier to read.

### Interested in EnableMe? Like to try it but need some help?

You can chat with us on EnableMe – use the green Helpdesk button at the bottom of your screen.

You can also call StrokeLine 1800 787 653 or email [strokeline@strokefoundation.org.au](mailto:strokeline@strokefoundation.org.au)





Photo © Chris Greer

## Jenny's story

The first three months after I went home were the hardest time. I lost my independence as I could no longer drive, and my husband had to become my carer as well as my taxi driver. I also found that my moods were up and down and my reactions to things felt out of proportion. I was bewildered as I'd never felt like this before my stroke.

I did find it difficult to access information and support to help us manage. I first read of EnableMe in the Stroke Foundation newsletter – I thought it could really help me with stroke information. The idea of connecting with other survivors also really appealed to me.

As a senior I wanted to enter the world of technology – a big learning curve – and after my stroke I wanted to challenge my brain. It was certainly worth doing as EnableMe is wonderful. I discovered that my emotional changes are commonly experienced after stroke and that's helped me immensely. I would encourage senior stroke survivors to take on the challenge of technology as there is so much to learn and enjoy.

### Jenny, stroke survivor

## For family and carers

### Managing a hospital stay

As the person or people closest to the stroke survivor, you will be providing care from the moment they become unwell.

You may talk to the stroke team and be a part of decision-making. If your family member can't make decisions about their treatment you may be the person responsible for making decisions for them.

You may spend much of your time at the hospital. You may provide practical and emotional support to your family member and keep other family members and friends informed. You may help set rehabilitation goals and help with exercises and activities suggested by the stroke team.

All the while you'll have your own emotions about what has happened, and you'll be keeping everything going at home. At times you may feel stressed, overwhelmed and even isolated.

If people offer to help, take them up on it. You can ask a family member or friend to:

- › Take the lead on keeping other family and friends informed.

- › Organise a visiting roster so you can plan to take a break and get other things done.
- › Help out with your other responsibilities – transport, shopping, school lunches, meals, childcare, homework help, household chores, dog walking and putting out the bins.

Having a family member in hospital is a busy and stressful time. Make sure to take time to rest.

### Get help

Your team's social worker can help with advice and support.

If you are talking to children about a family member's stroke, ask your stroke team for a copy of our Supporting children fact sheet. You can also:

- › Visit [strokefoundation.org.au](https://strokefoundation.org.au)
- › Call StrokeLine **1800 787 653**.
- › Gather My Crew is an online help roster that makes it easy to coordinate offers of practical support. Visit [gathermycrew.org.au](https://gathermycrew.org.au)



## 3. How do I take care of my health?

After a stroke, taking care of yourself is important.

Most survivors worry about their health and about having another stroke. The good news is there are things you can do to improve your health and reduce your risk of having another stroke.

After a stroke it's important to:

- › Talk with your stroke team – ask questions and share any concerns.
- › After you leave hospital, attend any appointments arranged by hospital staff and see your general practitioner (GP) regularly.
- › Take the medication you are prescribed.
- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke.
- › If you drink alcohol, drink only a safe amount. Read page 47 for advice.

### Causes of stroke

Your stroke team will tell you about your risk factors. If known, they'll tell you the cause of your stroke. Older age, being male, family history of stroke and having already had a stroke all increase your risk. You can't change these things but there are risk factors you can manage.

The most common medical risk factors are:

- › High blood pressure.
- › High cholesterol.
- › Atrial fibrillation (irregular heart rhythm).
- › Diabetes.

Lifestyle factors also increase your risk. These include:

- › Smoking.
- › Having an unhealthy diet.
- › Unhealthy weight.
- › Being inactive.
- › Drinking too much alcohol.

### Other conditions

There are some other conditions that may increase your risk of stroke, including:

**Aneurysm.** A thin or weak spot on an artery wall. It can 'balloon out' and burst, causing a haemorrhagic stroke.

**Arteriovenous malformation (AVM).** A tangled mass of arteries and veins, usually present at birth. As you get older, the arteries and veins get bigger and weaker and the walls can burst, causing a haemorrhagic stroke.

**Patent foramen ovale (PFO).** A hole in the heart that can allow blood clots to pass into the arteries, causing a stroke.

**Contraceptive pill, hormone replacement therapy and pregnancy.** Taking the contraceptive pill, using hormone replacement therapy (HRT) and pregnancy can increase the risk of stroke.

The contraceptive pill increases the risk of blood clots forming. HRT also increases the risk of blood clots forming, and it can increase your blood pressure. Pregnancy causes the levels of female hormones to rise, causing changes in the blood and the blood vessels. Blood pressure can also rise during pregnancy.

Rarer disorders that can cause stroke are often hereditary, meaning they are passed down through families.

Blood vessel disorders cause changes in the arteries, causing problems with the blood supply to the brain. These include:

- › Fibromuscular dysplasia (FMD).
- › Moyamoya disease.
- › Fabry disease.
- › CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy).
- › Cerebral amyloid angiopathy (CAA).

## Cryptogenic stroke

When a cause can't be determined it's called a cryptogenic stroke. Even if the cause of your stroke is unknown, it is important to understand all the risk factors and how to manage them.

## Medical risk factors

### High blood pressure

High blood pressure is the biggest risk factor for stroke. High blood pressure is also called hypertension.

Your heart pumps blood through your body and brain. Blood pressure is a measure of the force with which blood presses on the walls of your arteries as it is pumped around your body.

If your blood pressure is too high, your arteries can thicken over time. They become weaker and less flexible. High blood pressure also increases the chance of blood clots forming.

### Reduce this risk

- › Take anti-hypertensive medication to lower blood pressure.
- › Ask your doctor or pharmacist to check your blood pressure regularly. You can also buy a monitor and check it yourself.
- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke.
- › Keep salt to the recommended amount.
- › If you drink alcohol, drink only a safe amount. Read page 47 for advice.

120

80

### Blood pressure is measured with two numbers:

Systolic pressure. The force your blood puts on the blood vessel walls as your heart pumps.

Diastolic pressure. The force your blood puts on blood vessel walls when your heart is resting between beats.

**Normal blood pressure is around 120/80. If your blood pressure is regularly over 140/90, you have high blood pressure.**



## High cholesterol

High cholesterol can lead to fatty build-up in the arteries. It narrows or blocks the artery to the brain, and this can cause a stroke. High cholesterol is also known as hyperlipidaemia.

There are two types of cholesterol:

- › **Low density lipoprotein (LDL)** is the cholesterol that builds up on the artery walls. The more LDL you have, the higher your risk of stroke.
- › **High density lipoprotein (HDL)** is the cholesterol that removes cholesterol from the blood stream. The more HDL you have, the lower your risk.

## Reduce this risk

- › Take medication to lower cholesterol – most often statins.
- › Ask your doctor to check your cholesterol regularly.
- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke.
- › Reduce the amount of saturated fat in your diet. Read page 46 for advice.

## Atrial fibrillation

Atrial fibrillation (AF) is an irregular heart rhythm. AF can cause a blood clot to form in the heart. The clot can then travel to the brain, causing a stroke.

A doctor or nurse will check your pulse. Your pulse should tick like a clock. If it feels irregular, they will arrange an electrocardiogram (ECG) test.

For most people, medication will be enough to control their AF. Medication is used to control the heart's rhythm and to slow the heart rate. Anticoagulants ('blood thinners') are used to reduce the risk of blood clots forming and causing a stroke.

For some people, other treatment may be needed.

## Reduce this risk

- › Take the medication you are prescribed.
- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke.

## Diabetes

Uncontrolled diabetes can lead to your artery walls becoming hard and narrow. Diabetes also increases the chance of blood clots forming.

Blood sugar levels can be managed with medication, diet and exercise. Monitoring your blood sugar levels regularly is important. Ask your doctor or pharmacist if you are unsure about your monitoring or medication. Your doctor or pharmacist can arrange a review of your diabetes medications at any time.

### Reduce this risk

- › Take the medication you are prescribed.
- › Monitor your blood sugar levels regularly.

- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke.
- › If you drink alcohol, talk to your doctor about what is a safe amount for you. Read page 47 for advice.

### Get help

Diabetes Australia provides information and support about living with diabetes.

Call the Diabetes Australia helpline **1300 136 588** or visit [diabetesaustralia.com.au](http://diabetesaustralia.com.au)



## Lifestyle risk factors

### Smoking

Smoking increases your risk of stroke by increasing blood pressure and reducing oxygen in the blood. The chemicals in tobacco narrow and harden your arteries. The chance of blood clots increases and this can cause a stroke.

It's never too late to stop smoking. Once you stop, your risk of stroke starts to drop immediately.

It can be hard to quit smoking – asking for advice and support will help.

### Reduce this risk

Be smoke-free.

### Get help

Speak to your doctor and pharmacist about quitting. See a psychologist or other allied health professional if needed.

Contacting Quitline increases your chance of quitting successfully. Get free advice from a Quit expert, create a personalised quitting plan online and sign up for text and email support.

Call Quitline **13 7848** or visit [quitnow.gov.au](http://quitnow.gov.au)

### Being inactive

Not moving enough can lead to high blood pressure and cholesterol, increasing your risk of stroke.

Aim to be active for 30 minutes most days. It's okay to start small and build up gradually. Your 30 minutes can be made up of smaller bursts throughout the day. Exercise at a light to moderate intensity – you should be able to talk while exercising.

Start by setting a goal about how active you want to be and what you want to do. Think about the small things you can do every day to help you achieve your goal. Get into activities you enjoy and invite family and friends to join in.

### Reduce this risk

Increase the amount of activity you do every day.

### Get help

Speak to your doctor about exercising safely and see a physiotherapist or other allied health professional if needed.



## Mandy's story

I had my first cigarette at the age of eight. I know that's shocking but it was just with a girlfriend. We pinched one out of her mum's packet and we smoked it on the way back to school after lunch, and I thought this isn't bad. It's only one.

Before my stroke I was probably up to 45 a day. Just before I had my stroke, I was outside having a cigarette with my girlfriend Joy from work. I walked back inside and life changed forever.

I was closing up the shop and I was counting money. I kept dropping it with my right hand. I spoke to a workmate and she looked at me and said 'What are you saying?' It was just slurring, it wasn't coming out correctly. I thought 'I think I'm having a stroke'.

Then it all just went from there. I had a cigarette 45 minutes earlier, and all of a sudden I'm thinking 'I'm having a massive stroke'.

It was after my stroke I worked out I treated smoking like a best friend. All emotions, happy, sad, it was there. No matter where you looked it was always there.

Change the habits, change the lifestyle. Instead of getting up in the morning and flicking the kettle on and walking outside to have a cigarette, maybe go to the fridge, get a bottle of water and go for a ten-minute walk.

Don't give up quitting, just keep trying. If I can quit, you can quit.

**Mandy, stroke survivor**

## Unhealthy weight

Being overweight can lead to high blood pressure, high cholesterol and diabetes, increasing your risk of stroke.

Body mass index, or BMI, is one way to assess whether your weight is in the healthy range. Your waist circumference is another way.

Your doctor can give you advice on what is a healthy weight for you.

Getting to a healthy weight can take time. To get to and maintain a healthy weight, you'll need to understand what changes you need to make to your diet and how active you are.

Start by setting a small goal and think about the everyday things you can do that will help. Once you reach this goal, set another one.

## Reduce this risk

Find out what changes you need to make to your diet and how active you are.

Set goals to get to and maintain a healthy weight.

## Get help

Speak to your doctor and see a dietitian or other allied health professional if needed.

The Australian Government's Healthy Weight Guide website has information on getting to and maintaining a healthy weight. You can set goals, make a plan and track your progress. They have great advice on overcoming hurdles and staying motivated.

Visit [healthyweight.health.gov.au](https://healthyweight.health.gov.au)

## Rethink your diet after a stroke

**Saturated fats.** These cause high cholesterol. Choose mostly polyunsaturated and monounsaturated oils and spreads.

**Salt.** Too much salt can raise your blood pressure. Aim to consume less than four grams of salt each day. This is about three-quarters of a teaspoon. It's equivalent to 1600 milligrams sodium.

Packaged and processed food already has salt in it. Include more fresh food in your diet. Don't add salt when cooking or at the table.

**Sugar.** Too much sugar can damage blood vessels. Ease up on sweets, cakes, biscuits and chocolate. Avoid sugary drinks such as soft drinks, energy drinks, and fruit drinks with added sugar.

**Check the Health Star Rating and the Nutrition Information panel.** The Health Star Ratings on food packets are managed by the Australian Government. Health Star Ratings provide a quick and easy way to compare similar packaged foods. The more stars, the healthier the choice.

The Nutrition Information panel provides more detailed information on the amount of energy, protein, fat, saturated fat, carbohydrate, sugars and sodium (part of salt) in the food.

## Unhealthy diet

Having an unhealthy diet increases your risk of high blood pressure and cholesterol, increasing the risk of stroke. Eating a healthy diet will reduce this risk. It will also help you get to and maintain a healthy weight.

## Reduce this risk

- › Eat a wide variety of nutritious foods, including plenty of vegetables, fruit, grains and cereals.
- › Include lean meats and poultry, fish, eggs, tofu, nuts and seeds.
- › Eat dairy foods or their alternative, choosing mostly reduced fat.
- › Drink plenty of water.
- › Limit the amount of salt, sugar and saturated fat in your diet.

## Get help

Speak to your doctor and see a dietitian, psychologist or other allied health professional.

The Australian Government's Eat for Health website has advice about the amount and kinds of food we need to eat to be healthy. Visit [eatforhealth.gov.au](http://eatforhealth.gov.au)

## Alcohol

Drinking too much alcohol contributes to several risk factors for stroke, including high blood pressure. For healthy people, drinking no more than two standard drinks on any day reduces the risk of harm. After a stroke, you need individual advice from your doctor.

## Reduce this risk

- › If you drink alcohol, speak to your doctor about when it is safe for you to start drinking alcohol again. Ask how much alcohol it is safe for you to drink.

## Get help

The Australian Government's alcohol website has guidelines, tips to reduce your risk when drinking and links to support services. Visit [alcohol.gov.au](http://alcohol.gov.au)

### What is a standard drink?



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### What does a standard drink look like?



\* This information is a guide only and has been sourced from the Australian Government Department of Health at [alcohol.gov.au](http://alcohol.gov.au)

## Medication after stroke

After a stroke, almost everyone will need to take medication for the rest of their life. Medications to lower blood pressure and cholesterol are usually prescribed, even if your blood pressure and cholesterol are normal. These medications have been shown to reduce the risk of another stroke.

It's likely you'll be taking new or different medications after your stroke. Make sure you understand:

- › What your medications do.
- › How long you'll need to take them.
- › What monitoring or follow up you need.

Remember:

- › Ask your doctor or pharmacist if you are unsure or have questions.
- › Your doctor or pharmacist can arrange a review of your medications at any time.
- › Never stop taking your medication or change your dose without talking to your doctor.

Make sure you have a list of medications when you leave hospital. Take this list to all your follow up medical appointments.



## My fact sheets – risk factors

Read our fact sheets to learn more about ways to manage your risk factors and reduce your risk of having another stroke.

Your stroke team can give you copies. You can also:

- › Visit [strokefoundation.org.au](http://strokefoundation.org.au)
- › Call StrokeLine **1800 787 653**.

Tick box	Risk factor	Who can I ask about this?	Fact sheet
	High blood pressure	Doctor Nurse Dietitian Physiotherapist	Medication
	High cholesterol	Doctor Nurse Dietitian	Medication
	Atrial fibrillation (irregular heart beat)	Doctor Nurse	Medication
	Diabetes	Doctor Nurse Dietitian	<a href="http://diabetesaustralia.com.au">diabetesaustralia.com.au</a>
	Smoking	Doctor Pharmacist Psychologist	<a href="http://quitnow.gov.au">quitnow.gov.au</a>
	Being inactive	Doctor Physiotherapist	Fatigue Mobility and exercise Pain Upper limb management
	Unhealthy diet	Dietitian	Diet
	Being overweight	Nurse Dietitian Psychologist	Diet Mobility and exercise
	Drinking too much alcohol	Doctor Psychologist Social worker	Alcohol

## Signs of stroke

It's important for everyone to know the signs of stroke.

Never ignore the signs. Always call triple zero (000).

Medical treatment may lessen the impact and improve your chance of survival, but it depends on getting to hospital quickly.

The F.A.S.T. test is an easy way to remember the most common signs of stroke.

There can be other signs, such as:

- › Numbness, clumsiness, weakness or paralysis of the face, arm or leg on one or both sides.
- › Dizziness (especially 'head spins'), loss of balance or an unexplained fall.
- › Loss of vision in one or both eyes.
- › Headache, usually severe and sudden.
- › Difficulty swallowing.
- › Nausea or vomiting.

Remember, even if you aren't sure it's a stroke, call triple zero (000). The operator will decide what needs to happen next. Triple zero (000) operators are experts in making these decisions.

### What is a TIA?

A transient ischaemic attack (TIA) happens when the blood supply to your brain is blocked **temporarily**. When the blood supply stops, the brain cells in the area start to shut down, and you experience signs something is wrong.

If the blockage clears, the blood supply starts again and the signs disappear. A TIA will have no lasting impact, making it different to a stroke.

A TIA is a warning that you may have a stroke and an opportunity to prevent this from happening. Never ignore the signs, even if they disappear. Always call triple zero (000).

The infographic features a dark blue header with the text "Recognise **STROKE** Think *F.A.S.T.*". Below this, four panels illustrate the F.A.S.T. test: 1. **F**: "Has their **FACE** drooped?" with a photo of a woman's face. 2. **A**: "Can they lift both **ARMS**?" with a photo of hands holding a red cup. 3. **S**: "Is their **SPEECH** slurred and do they understand you?" with a close-up of a person's mouth. 4. **T**: "Call 000, **TIME** is critical" with a photo of a hand holding a smartphone. At the bottom, a dark blue bar contains the text "If you see any of these symptoms **Act FAST call 000**" and the Stroke Foundation logo.

## Tips for getting good healthcare

### Ask questions

Ask lots of questions, and let your team know when you don't understand something.

### Write things down

Start by writing things in this book. You can also use an exercise book, diary, tablet or phone. Keep a list of the questions you want to ask. Take notes about the information you receive.

Write down the names and contact details of health professionals involved in your care. If you can't write easily, ask them to write their details down for you. Family and friends can help with this too.

### Talk about your concerns

If you have concerns, speak to the health professional involved or to the nurse unit manager.

You can also talk to the hospital patient advocate or consumer liaison officer.

Find them by:

- › Asking the nurse unit manager.
- › Calling the hospital and asking to be put through.
- › Checking the hospital's website.

### Call StrokeLine

StrokeLine's health professionals can help with information, advice, support and referral. Call StrokeLine **1800 787 653** or email [strokeline@strokefoundation.org.au](mailto:strokeline@strokefoundation.org.au)





## William's story

One of the biggest changes we may have to go through in our stroke recovery is changing how we view ourselves.

I like to think of recovery as being like an artist painting a self portrait.

Before our stroke, we had a very strong sense of who we were, what we valued and what we didn't. Then one day, all of a sudden, white paint is spilt all over our self portrait, leaving it blank.

Devastated by what's happened, we eventually start to paint a new portrait. We start with big, broad strokes because it's always messy in the beginning. As we progress in our recovery, our brush strokes start to become finer with each milestone along the journey.

With each brush stroke we gain a greater understanding of ourselves. After years of work, we are able to stand back and marvel at what has been painted. We barely remember what the old portrait looked like. Although this one looks different, we identify with it more than our original one.

After my stroke, I found there was a huge emphasis on 'getting back to normal'. One of the things I really struggled with was accepting that I needed to ask for help or do things differently. Being someone used to doing things myself, I did everything in my power to cling to this. It was at the core of my identity.

After a stroke, I think it's important to recognise it as a learning opportunity. It's a chance to put more work into yourself, to reach your potential, and not to box yourself into how you or other people have defined you.

**William, stroke survivor**

## For family and carers

### Family meetings

A family meeting brings together the survivor, their family and members of the stroke team. Your stroke team may suggest a family meeting. You can also request a family meeting. Family meetings are a good time to ask questions and to raise any concerns or worries.

Family meetings can help:

- › The exchange of information between you, your family and the stroke team.
- › Make decisions about treatment, care and rehabilitation.
- › Make plans for leaving hospital.

To prepare for a family meeting:

- › Ask for an interpreter if anyone in the family needs one.
- › Write down the things you want the team to know and the questions you want to ask.
- › As much as possible, make sure family members who should be there are there. Family members can telephone into the meeting if needed.

Take notes or ask the team if they can provide a written summary after the meeting. It can help to include a family member who is mainly there to take notes and provide support.

### Decision making

All adults have the right to make their own decisions. However, if a person becomes unable to make reasoned decisions because of illness or disability, there are laws to determine how decisions can be made for them.

### Person responsible

If you are sick or injured and can't make decisions about your medical treatment, your doctor can ask someone else to make a decision for you. Each state has rules for deciding who this person is.

### Enduring powers of attorney

Gives someone you nominate the legal ability to make decisions for you when you are unable to make decisions for yourself.

Enduring powers of attorney can only be made when you have legal capacity. This means you fully understand the nature and effect of the document you are completing and the nature and extent of your affairs.

### Guardianship and administration

Where there is no enduring power of attorney, there is a legal body in each state that can appoint a decision maker if needed.

A guardian can make lifestyle or personal decisions. An administrator can make financial decisions.

### More help

Your social worker and treating team can provide advice.

Each state has an organisation to provide advice on decision making. These are called the Office of the Public Advocate or Public Guardian. Talk to your social worker or call StrokeLine **1800 787 653** for details.

## StrokeLine

StrokeLine's health professionals provide information and advice on stroke prevention, treatment and recovery. The StrokeLine team can help you and your family find the support and services you need. The service is free and provides confidential advice to help you manage your health better and live well.

“

We know the stroke journey can be a roller coaster. That's why we're here to help every step of the way.

Our team includes occupational therapists, physiotherapists, speech therapists and social workers. Between us we have many decades of stroke care experience.

On StrokeLine we take time to listen. We will tell you about the things that can help, and the resources and services available to you. You'll come away from your contact with StrokeLine with a plan that works for you.”

**Simone**, StrokeLine occupational therapist

Call StrokeLine **1800 787 653**

Monday to Friday 9am to 5pm, Eastern Standard Time

Email [strokeline@strokefoundation.org.au](mailto:strokeline@strokefoundation.org.au)

### Using an interpreter to call StrokeLine

If you or a family member would like to speak to StrokeLine with the help of an interpreter, just follow these steps:

- › Call the Telephone Interpreting Service **13 14 50**.
- › Say the language you need and wait on the line for an interpreter.
- › Ask the interpreter to call StrokeLine **1800 787 653**.









## Julie's story

Ross was in hospital for a long time and the entire focus was on getting him well enough to come home. You always put yourself last, you put your spouse and your children first. It's a difficult thing for carers, to find that balance. That's been one of the benefits of the carer's group, to talk to people who understand what you're going through.

My advice is to try to do one thing at a time, not to try to do everything at once. Though it's hard – my mind goes in lots of different directions! For me it's one day at a time, one thing at a time. I work out what I can do, and I get help for the things and for the times that I can't. Finding out where to get help from can be difficult, it takes a lot of persistence. I always ask a lot of questions of everyone I meet.

Make sure you say yes to everything. If someone says "would you like a follow up appointment?" the answer is always yes. Don't say no to anything. If it doesn't fit in later on, or you find you don't need that service, you can say no then.

I learnt that I'm tougher than I think. Our family is pretty tough too, and we have a great group of friends. I'm an emotional wreck sometimes, and that comes with being tired. But I'm pretty tough. Sometimes you think about all the things that you've lost, but then you think about all the things you've got. I've got my health, and I've got Ross – between us we can work through things. Being a carer is a challenge, but I wouldn't be anywhere else.

**Julie, carer**

## 4. What happens after my hospital stay?

### Planning to leave hospital

Your stroke team will talk with you about planning to leave hospital. This is called discharge planning.

A good discharge plan relies on good communication between the stroke team, you, your family members, your general practitioner (GP) and anyone else helping you at home. Discharge planning helps make sure you continue to get the right healthcare from the right people after leaving hospital. It also helps make sure you are safe and well after you leave hospital.

After your hospital stay, you may go home, go to an aged care home or you may need palliative care.

### Going home

Getting ready to go home will include thinking about the things you need to do every day. You will need to know how to do things safely. Anyone who will be helping you also needs to be shown how to help you safely. Your stroke team will help you with this.

Modifications to your home and special equipment may be needed. You might also need some services to help.

Further rehabilitation, and follow up tests and appointments may also need to be organised. You'll also need enough medication to last until you see your GP.

### Going to an aged care home

Aged care homes are for older people who have care needs that can't be met at home. They provide 24-hour nursing and personal care.

The stroke team will often arrange a family meeting to discuss the person's care needs and why an aged care home is needed.

Sometimes there are different opinions about whether an aged care home is needed. Your social worker can help work through these issues. The hospital's patient advocate or consumer liaison officer can also provide advice.

Only an Aged Care Assessment Team (ACAT) can approve a person for an aged care home. The hospital will arrange the ACAT assessment. It will be up to a family member to visit homes and to decide which ones to apply to. Your stroke team's social worker will provide advice and support throughout the process.

## Going to palliative care

Palliative care is care for the physical, emotional and spiritual needs of someone with a serious illness that cannot be cured. Palliative care eases symptoms and provides comfort to people who are dying and to their families.

Palliative care may be provided in hospital, in a palliative care unit or in an aged care home. It can also be provided at home with support from a palliative care team and family members.

Your stroke team will talk to you about palliative care if needed.

## The discharge summary

A discharge summary is prepared while you are in hospital or shortly after you leave. You and your GP will receive a copy of the summary.

It explains:

- › Why you were admitted to hospital.
- › What tests were done and what treatment you received.
- › What medications you are taking.
- › What services and follow up appointments have been arranged.

Make sure you have a list of your medications when you leave hospital. Take this list with you to your GP. Take it to any other follow up medical appointments too.



# My appointments and services

## Appointments

Speak with your stroke team about follow up appointments and how they will be organised. Write the details in the space below. Details about some appointments may be sent to you after you leave hospital.

Appointment	Date and time	Contact details

## Services

Speak with your stroke team about services and how they will be organised. Write the details in the space below.

Service	Notes	Contact details





## My leaving hospital checklist

### Who to contact

I know who to contact if I have questions about my hospital stay.

### Follow up tests and appointments

I know what follow up tests and appointments I need.

I know how these will be organised.

### Services

I know what services I need.

I know how these will be organised.

### Daily life

I know how to do the things I need to do every day safely.

The people helping me know how to help me safely.

### Home modifications

I know what changes I need to my home.

I know how these will be organised.

## Equipment

- I know what equipment I need.
- I know how this will be organised.

## Rehabilitation

- I know what rehabilitation I need.
- I know how this will be organised.

## Medication

- I have a list of my medications.
- I know why I take each of my medications.
- I have enough medication to last until I see my GP.

## Risk factors

- I know how to manage my stroke risk factors.

## Signs of stroke

- I know the signs of stroke – F.A.S.T.
- I know to call triple zero (000) if I experience the signs.

## For family and carers

### Becoming a carer

As the time to leave hospital gets closer, you may find yourself taking on a carer role.

Some carers look after another person 24 hours a day. They help with all sorts of things, like feeding, bathing, dressing, helping go to the toilet, lifting and moving, and helping with medicines.

Other carers look after people who are fairly independent but might need someone to help with everyday tasks such as banking, transport, shopping and housework.

It is normal for carers to feel love for their family member and pride in themselves and their family. It's normal to feel grateful that your family member survived, and for the care they received. It's also normal to feel angry, resentful, scared, guilty and sad.

Becoming a carer might not be something you had ever imagined. While caring for another person is an expression of our love, respect and connection, it can take a toll. The impact on you can get lost amongst all the demands.

It helps to talk to a trusted family member or friend about how you are feeling. You can also talk to your social worker. You can also get support from a service for carers.

### Getting ready to care at home

There may be things the survivor will need help with once they get home. It's important to talk to the stroke team about what life will be like at home.

You'll need to be shown the safe way to do things, whether the survivor is doing them independently or whether someone is helping. Training, practice and equipment may be needed.

Make sure the stroke team understand your other responsibilities. Make sure you are clear about anything you don't feel comfortable doing. Services may be available to help.

Before going home, make sure you feel confident about the plan to go home. Make sure you know who to ask if you need help. Make sure any questions you have are answered before you leave hospital.

### Carer payments and services

Carer payments are available for people who provide care at home for someone with a severe disability, medical condition or who is frail and aged. Eligibility depends on your circumstances, and there is an income and assets test.

Respite care is a short-term care provided in your home, or for longer periods in an aged care home. It can be planned or arranged in an emergency if needed.

Counselling is also available for carers. Staff in these services understand the ups and downs of caring and know what can help.

### Get help

Your stroke team's social worker can provide support, as well as information about carer services and payments.



**Centrelink** can provide advice on payments. Call **132 717** or visit [humanservices.gov.au](http://humanservices.gov.au)

**The Carer Gateway** can provide information on counselling and other services. Call **1800 422 737** or visit [carergateway.gov.au](http://carergateway.gov.au)

**Relationships Australia** provides counselling to individuals, couples and families to support positive and respectful relationships. Call **1300 364 277** or visit [relationships.org.au](http://relationships.org.au)

## Depression and anxiety

Depression and anxiety are common after stroke. Stroke survivors, carers and family members can all experience depression and anxiety.

It's normal to feel sadness and grief in the time shortly after the stroke. These feelings should start to fade as time passes. If some time has passed and you are still feeling down or anxious, or struggling to cope with how you are feeling, you may need some help.

You may have depression if you feel sad or down for more than two weeks. You may lose interest in things you normally enjoy, lack energy, have difficulty sleeping, or sleep more than usual. You may find it difficult to concentrate, to solve problems and to keep appointments.

You may have anxiety if anxious feelings do not go away once a stressful situation is over, or if you are anxious for no particular reason.

Never ignore the signs of depression or anxiety. Depression and anxiety are highly treatable and recovery is common.

## Get help

Speak to your doctor or other health professional.

### Lifeline

Lifeline provides all Australians experiencing a personal crisis with online, phone and face-to-face crisis support and suicide prevention services.

Call **13 11 14** (24 hours) [lifeline.org.au](http://lifeline.org.au)

### beyondblue

beyondblue provides helps with anxiety, depression and suicide prevention. beyondblue provides information and support to help everyone achieve their best possible mental health.

Call **1300 22 4636** [beyondblue.org.au](http://beyondblue.org.au)

## Fear of having another stroke

For anyone who's had a stroke, one of the biggest fears is it happening again. Having a plan and taking action to reduce your risk of stroke can help.

While being afraid of having another stroke is very normal, it can become overwhelming. If some time has passed and you are struggling to cope with how you are feeling, you may need some help.

### Get help

Speak to your doctor or allied health professional about how you are feeling.

## Fatigue and sleep

After you get home you may notice your fatigue is worse. You may notice the effects of your stroke more too, and feel like you are getting worse not better. This is very common as you get back into daily life and start doing more things for yourself. Speak to your doctor or allied health professional if you have questions or concerns.

You may also have changes with your sleep. Not getting a good night sleep can affect your thinking, mood, energy levels and appetite. Sleep-related breathing disorders can also develop after a stroke.

Getting enough good-quality sleep is an important part of recovery. Good 'sleep hygiene' will help you get a good night's sleep. It includes:

**Work with your body clock.** Get up at the same time every day, get enough early morning sunshine and go to bed when your body tells you it's ready.

**Create a restful sleep environment.** Make sure your bed and bedroom is comfortable, dark and quiet. Use earplugs if necessary. Use your bedroom only for sleeping and intimacy.

**Avoid caffeine, cigarettes, drugs and alcohol.** Sleeping pills should only be used as a temporary last resort and under medical advice.

**Relax before going to bed.** Consciously do your worrying earlier in the day so you can 'knock off' at bedtime. Create a relaxing routine and try relaxation exercises.

### Get help

If you are having difficulties sleeping, talk to your doctor or health professional.

For information and advice, call StrokeLine **1800 787 653**.

## Driving and transport

It's important to follow the rules about driving after a stroke or TIA. You must:

**Wait.** Don't drive for two weeks after a TIA or four weeks after a stroke. These times are longer if you hold a commercial licence.

**Check with the licensing authority.** The laws are different in each state and territory. It is your responsibility to know the rules in your state or territory.

**Speak to your doctor.** You need medical clearance to return to driving. Your doctor can clear you to drive if you have made a good recovery from the stroke and you don't have any remaining impairments affecting your ability to drive.

**Have a driving assessment if needed.** Your doctor may recommend an occupational therapy driving assessment if you have impairments after your stroke.

If you're unable to return to driving, community services may be able to help with transport for shopping and medical appointments. People with a severe and permanent disability can also apply for subsidised taxi travel – contact the taxi authority in your state.

## Get help

State transport authorities provide information regarding medical conditions and driving.

Australian Capital Territory **13 22 81**  
[accesscanberra.act.gov.au](http://accesscanberra.act.gov.au)

New South Wales **132 213**  
[rms.nsw.gov.au](http://rms.nsw.gov.au)

Northern Territory **1300 654 628**  
[nt.gov.au/driving](http://nt.gov.au/driving)

Queensland **13 23 90**  
[tmr.qld.gov.au](http://tmr.qld.gov.au)

South Australia **13 10 84**  
[sa.gov.au/topics/driving-and-transport](http://sa.gov.au/topics/driving-and-transport)

Tasmania **1300 135 513**  
[transport.tas.gov.au](http://transport.tas.gov.au)

Victoria **13 11 71**  
[vicroads.vic.gov.au](http://vicroads.vic.gov.au)

Western Australia **13 11 56**  
[transport.wa.gov.au](http://transport.wa.gov.au)

**Occupational Therapy Australia** provides a list of endorsed driving assessors. Call **1300 682 878** or visit [otaus.com.au](http://otaus.com.au)

For more information and advice, call StrokeLine **1800 787 653**.

## Work

If returning to work is one of your goals, talk to your stroke team or your GP. Support and good planning are needed to ensure things go smoothly.

Talk to your stroke team or your GP about the effects of your stroke, what to expect and strategies for a successful return to work. You may need:

- › Changes to your duties and the hours you work.
- › Equipment or modifications at work to make your job easier.

You can then speak with your employer about the support you need to return to work successfully.

When planning your return to work, keep in mind that fatigue can last longer than you expect.

Ongoing medical problems may prevent you from being safe or well enough to return to work. Medical clearance from your doctor is needed before you get back to work.

There are services to help you return to work, as well as services that can help if you cannot return.

### Get help

Centrelink – Jobs, Education and Training  
**132 850** [humanservices.gov.au](http://humanservices.gov.au)

JobAccess  
**1800 464 800** [jobaccess.gov.au](http://jobaccess.gov.au)

## Finances

Centrelink may be able to help with payments if you have an illness, injury, disability or carer responsibilities that mean you cannot work or can only do a limited amount of work. Centrelink may also be able to help with concession and health care cards. These cards may entitle you to discounts on:

- › Some health care services and prescription medicines.
- › Rates and utilities.
- › Vehicle registration and public transport.

Eligibility for help from Centrelink will depend on your circumstances.

After a stroke, you may be eligible for an early release of superannuation. You may also have disability insurance as part of your superannuation. Speak to your superannuation fund.

Financial counsellors provide free information, support and advocacy to people in financial difficulty. If you're struggling with your finances, seek help straight away.

### Get help

**Centrelink**  
**132 850** Newstart allowance

**132 717** Disability and carers

**132 850** Jobs, education and training  
[humanservices.gov.au](http://humanservices.gov.au)

## Financial counselling

The Australian Government Money Smart website provides advice on managing finances, along with links to financial counselling services. Their helpline can provide advice on managing debt.

National debt helpline **1300 300 630**  
[moneysmart.gov.au](http://moneysmart.gov.au)

## Other helpful services

### Lifeline

Lifeline provides all Australians experiencing a personal crisis with online, phone and face-to-face crisis support and suicide prevention services.

Call **13 11 14** (24 hours) [lifeline.org.au](http://lifeline.org.au)

### Aids and equipment

Independent Living Centres Australia  
**1300 885 886** [ilcaustralia.org.au](http://ilcaustralia.org.au)

### Continence

Continence Foundation of Australia  
**1800 33 00 66** [continence.org.au](http://continence.org.au)

### Vision

Information and services for people with vision loss.

Vision Australia **1300 84 74 66**  
[visionaustralia.org](http://visionaustralia.org)

Guide Dogs Australia **1800 484 333**  
[guidedogsaustralia.com](http://guidedogsaustralia.com)

## Stroke support groups

Stroke support groups are a good way to connect with others to share advice and support.

Some groups cater for everyone in a local area, while others cater for particular age groups and interests. There are groups for people with aphasia, and groups for carers.

For a list of stroke support groups, stroke choirs and aphasia groups across Australia, visit our website or call StrokeLine on **1800 787 653**.

If you live in Victoria, New South Wales or South Australia, your stroke association can help you find a stroke support group. Stroke associations also provide information and support to stroke survivors and carers in their state.

Stroke Association of Victoria  
**03 9670 1117** [strokeassociation.com.au](http://strokeassociation.com.au)

Stroke Recovery Association of NSW  
**1300 650 594** [strokensw.org.au](http://strokensw.org.au)

Stroke Association of South Australia  
**08 8352 4644** [stroke.org.au](http://stroke.org.au)

If you would like to know more about aphasia groups, contact:

Australian Aphasia Association  
**1800 274 274** [aphasia.org.au](http://aphasia.org.au)

Aphasia Community  
[www.aphasia.community](http://www.aphasia.community)

## Accessing allied health and rehabilitation services

Your stroke team may refer you to rehabilitation services as part of your discharge plan. After this ends you may want to see an allied health professional to:

- › Make lifestyle changes to control your risk factors.
- › Manage the impacts of your stroke.
- › Maintain the gains you have made or work towards new goals.

Options include:

**Medicare-subsidised sessions.** After a stroke, you can access five allied health sessions each year with a Chronic Disease Management Plan. To maximise these sessions make sure your allied health professional works with you to develop a plan for what you can do between sessions and after your subsidised sessions have ended for the year.

If you have been diagnosed with a mental health condition such as depression or anxiety, you can access 10 counselling sessions each year with a Mental Health Care Plan.

Access to Medicare-subsidised sessions is usually arranged by your GP. There is usually a gap payment so check this when you make an appointment.

**Your NDIS plan.** If you are eligible for the National Insurance Disability Scheme (NDIS), think about how allied health therapy may help you to better manage everyday activities and achieve your goals. Make sure what you need is considered in the planning process with NDIS.

**Private health insurance.** Talk to your provider about what is available to you. It may include access to allied health services or rehabilitation sessions at a private hospital.

**Community-based rehabilitation.** Ask your GP about community-based rehabilitation options. This is a good option if you need more than one type of allied health professional, if what you can do has changed or if you have new goals.

**Research and student clinics.** Research can involve testing a therapy so participation can help with recovery. Universities offer student clinics that can be a good way to access low cost allied health services. Visit [strokefoundation.org.au](http://strokefoundation.org.au) for information about research.

StrokeLine can help you with advice on your options. Call **1800 787 653** or email [strokeline@strokefoundation.org.au](mailto:strokeline@strokefoundation.org.au)

**Allied health associations.** These organisations can help you find a health professional with expertise in stroke. This can be helpful if you have funding or insurance to pay for allied health services.

Occupational Therapy Australia  
**1300 68 2878** [www.otaus.com.au](http://www.otaus.com.au)

Speech Pathology Australia **1300 368 835**  
[www.speechpathologyaustralia.org.au](http://www.speechpathologyaustralia.org.au)

Australian Physiotherapy Association  
**1300 306 622** [www.physiotherapy.asn.au](http://www.physiotherapy.asn.au)

Dietitians Association of Australia  
**1800 812 942** [www.daa.asn.au](http://www.daa.asn.au)

Australian Psychological Society  
**1800 333 497** [www.psychology.org.au](http://www.psychology.org.au)

## Help at home

If you need information about services to help you stay at home, there are two services that can help.

**My Aged Care.** If you are over 65 years of age, My Aged Care may be able to help. They can tell you about different local aged care services available, assess your eligibility for services and let you know about costs.

Call **1800 200 422** or visit [myagedcare.gov.au](http://myagedcare.gov.au)

**National Disability Insurance Scheme.** If you are under 65, the National Disability Insurance Scheme (NDIS) may be able to help. The NDIS helps people under 65 who have permanent and significant disability get the support they need.

Call **1800 800 110** or visit [ndis.gov.au](http://ndis.gov.au)



## My fact sheets – after hospital

Read our fact sheets to learn more about life after hospital.

Tick box	Who can I ask about this?		Fact sheet
	Aged care homes	Social worker	Aged care homes
	Palliative care	Doctor Social worker	Palliative care
	Driving	Doctor Occupational therapist	Driving
	Fatigue	Occupational therapist Physiotherapist	Fatigue
	Work	Doctor Occupational therapist	Return to work

Your stroke team can give you copies.

You can also:

Visit [strokefoundation.org.au](http://strokefoundation.org.au)

Call StrokeLine **1800 787 653**.

Learn more about life after your hospital stay by visiting our stroke recovery website [enableme.org.au](http://enableme.org.au)



## Strokesaurus

Here are the most common medical terms. See the full list at [enableme.org.au](http://enableme.org.au)

### Ankle-foot orthosis (AFO)

Plastic brace used to minimise tripping and reduce fall risks for people with foot drop.

### Aneurysm

A thin or weak spot on an artery wall. It can 'balloon out' and burst, causing a haemorrhagic stroke.

### Antihypertensive

Medication to lower blood pressure.

### Antiplatelet

Medication to stop blood cells called platelets from sticking together and forming clots. Also called platelet aggregation inhibitors.

### Anticoagulant

Medication to stop blood forming clots.

### Anxiety

If anxious feelings do not go away when a stressful situation is over or if you are anxious for no reason, you may have anxiety. Anxiety is highly treatable and recovery is common. Speak to your doctor or a member of your stroke team.

### Aphasia

Difficulty talking, reading, writing or understanding other people when they speak. Also called dysphasia.

### Aphonia

Being unable to make any sound at all.

### Apraxia

Difficulty planning movement.

### Aspiration

Swallowing difficulties cause food or drink to go down the wrong way and get into your lungs, causing an infection.

### Ataxia

Difficulty coordinating movements.

### Artery

Blood vessels that carry blood away from the heart.

### Arteriovenous malformation (AVM)

Tangled mass of arteries and veins, usually present at birth. As you get older, the arteries and veins get bigger and weaker and the walls can burst, causing a haemorrhagic stroke.

### Atrial fibrillation (AF)

Atrial fibrillation (AF) is an irregular heart rhythm. AF can cause a blood clot to form in the heart. The clot can then travel to the brain, causing a stroke.

### Botulinum toxin A

Medication which is injected into the muscles to treat spasticity. Also known as Botox.

### Carotid Doppler ultrasound

Ultrasound of the neck arteries to show if they are narrow or blocked.

## Carotid endarterectomy

Surgical treatment to remove plaque blocking the carotid arteries that carry blood to the brain.

## Cerebral angiogram

A small tube called a catheter is inserted through an artery in the arm or leg and moved up into the brain arteries. A dye is injected through the tube and X-ray images are taken. The images show how dye moves through the arteries and veins of the brain. Doctors can see if there is a problem with the blood supply to the brain and where the problem is.

## Cholesterol

A fatty substance in blood. High cholesterol can lead to build up in the arteries, narrowing or blocking the artery to the brain.

## Cognition

Thinking, memory and judgment.

## Computerised tomography (CT)

Scan that takes pictures of your brain to show areas of injury and swelling.

## Contracture

Muscle spasticity leads to muscles getting shorter, resulting in a joint becoming fixed in one position.

## Deep Vein Thrombosis (DVT)

A blood clot in the veins that can travel to the lung and cause pulmonary embolism (PE). Being unable to move,

or not moving as much, after a stroke increases the risk of DVT. Calf compression devices or anticoagulant medications are often used to prevent DVT.

## Depression

If you feel sad, down or miserable for more than two weeks, you may have depression. You may lose interest or pleasure in things you normally enjoy. You may lack energy, have difficulty sleeping, or sleep more than usual. You may find it difficult to concentrate, to solve problems and to keep appointments. Depression is highly treatable and recovery is common. Speak to your doctor or a member of your stroke team.

## Diabetes

Condition where the levels of sugar (glucose) in the blood are too high.

## Disinhibited

Saying or doing things that are not usual or expected. These things may seem inappropriate to others.

## Dysarthria

Weakness or paralysis in the muscles used for speaking, making speech slurred or unclear.

## Dysphagia

Difficulties with moving food around in your mouth and swallowing.

## Dysphonia

Weakness or paralysis in the muscles in and around the vocal chords make your voice sound whispery, hoarse or rough.

## Electrical stimulation

Weak muscles are activated by placing electrodes on the skin, stimulating nerves and muscles.

## Echocardiogram (Echo)

Ultrasound to look at the structure and function of the heart. An Echo can show if there is a blood clot in the heart, if the chambers of the heart are enlarged or the valves are not working properly.

## Electrocardiogram (ECG)

Electrodes placed on the skin of the chest to test for abnormal heart rhythm or heart disease.

## Electrolytes

Levels of salt (sodium and potassium) in the blood. This can be tested with a blood test.

## Emotional lability

Emotional responses that don't make sense or are out of proportion. You may cry or laugh uncontrollably. Also known as the pseudobulbar affect.

## Endovascular clot retrieval (ECR)

Physical removal of a blood clot from a large artery. A small tube called a catheter is inserted into an artery in the groin or arm and moved up into the brain arteries. A suction device or a metal net called a stent is used to capture and remove the blood clot that is blocking the artery and causing a stroke. Also called endovascular thrombectomy.

## Fasting lipids

A blood test for cholesterol levels.

## Fibreoptic endoscopic evaluation (FEES)

A camera is attached to a thin tube and inserted into your nose to check your swallowing.

## Foot drop

Weakness or contracture cause the foot or ankle to drop down.

## Full blood examination (FBE)

A blood test that looks at red blood cells, (which are reduced in people with anaemia). It also looks at white blood cells, which are increased in people with infections. An FBE also looks at platelets, which help blood clot.

## Glucose test

A blood or finger print test for blood sugar levels.

## Haematocrit test

Test for iron levels.

## Haemorrhagic stroke

Stroke caused by bleeding in the brain when an artery breaks or bursts.

## Hemianopia

Your visual field is the entire area that can be seen when your eye is directed forward. Hemianopia is the loss of one half of the visual field in each eye.

## Hemiplegia

Paralysis on one side of the body.

## Hemiparesis

Weakness on one side of the body.

## Hemisphere

The sides of the brain – left or right.

## High blood pressure

Blood pressure is a measure of the force with which blood presses on the walls of your arteries as it is pumped around your body. If your blood pressure is regularly over 140/90 you have high blood pressure. Also known as hypertension.

## Holter monitor (ECG)

A wearable device measures your heart activity continuously over time.

## Homonymous hemianopia

Your visual field is the entire area that can be seen when your eye is directed forward. Homonymous hemianopia is the loss of one half of the visual field in each eye.

## Hypersensitivity

Increased feeling or sensitivity.

## Hypertension

High blood pressure.

## Hypotonia

Muscles are floppy or loose.

## Impulsive

Acting without thinking. You may do things that are unexpected or unsafe.

## Infarct

Area of the brain that has been injured due to stroke.

## Insight

Understanding the effects of your stroke and how they impact you.

## International Normalised Ratio (INR)

Test that shows the time it takes for your blood to clot.

## Intracerebral haemorrhage

Small blood vessel in the brain bursts causing bleeding in the brain.

## Iron Studies

A blood test for iron storage levels.

## Ischaemic stroke

Stroke caused by an artery in the brain being blocked by a blood clot.

## Judgement

Ability to make good decisions.

## Leukocyte test

Test that shows white blood cell count.

## Lobes

Different areas of the brain.

## **Magnetic resonance imaging (MRI)**

Scan that takes pictures of the brain to show areas of injury and swelling.

## **Mobility**

Moving, walking and standing.

## **Muscle spasticity**

High tone or activity in muscles makes them feel stiff and tight. Also called hypertonia.

## **Nasogastric tube (NG tube or NGT)**

A tube is passed through one nostril down the back of your throat and into your stomach. Special liquids that meet your nutritional needs and medications go through the tube.

## **Neglect**

Not being aware of things or your body on one side. Also called inattention, visual neglect or hemispatial neglect.

## **Neuropathic pain**

Pain caused by damage to the brain's pain-processing pathways. Also called central post stroke pain (CPSP) or nerve pain.

## **Neuroplasticity**

The brain's ability to change. The damaged area of the brain may repair itself and start working again. Other parts of the brain can take over the tasks the injured area used to do. Practice and repetition of tasks is vital to promote neuroplasticity.

## **Novel Oral Anticoagulants (NOACs)**

Medication to stop your blood forming clots. Also called Direct Oral Anticoagulants (DOACs)

## **Nystagmus**

Constant, unsteady or jerking movement of the eyes.

## **Oedema**

Swelling due to fluid build up.

## **Orientation**

Knowing things like the day, date or where you are.

## **Patent foramen ovale (PFO)**

A hole in the heart that can allow blood clots to pass into the arteries, causing a stroke.

## **Percutaneous endoscopic gastrostomy (PEG)**

A tube is inserted through the skin in your abdomen. Special liquids that meet all of your nutritional needs and medications go through the tube.

## **Perception**

Understanding what you see, hear, smell, taste and feel.

## **Perseveration**

Getting stuck on one idea, action or response.

## Recognition

Knowing what things like objects or parts of your body are.

## Quadrantanopia

Your visual field is the entire area that can be seen when your eye is directed forward. Loss of either the upper or lower quarter of the visual field.

## Subarachnoid haemorrhage (SAH)

Bleeding under the membrane surrounding the brain, usually because of a burst aneurysm.

## Short-term memory

Ability to remember things that happened a short time ago and to retain that memory.

## Statins

Medication used to control cholesterol levels.

## Shoulder subluxation

Changes in the muscle cause your upper arm bone to sit slightly lower in your shoulder socket.

## Strabismus

A nerve that controls eye muscles stops working causing eye turning.

## Thrombolysis

A drug is given to dissolve a clot in an artery in the brain that is causing a stroke. It is given as an intravenous injection in your arm.

## Transcranial Doppler (TCD)

Ultrasound to measure the speed of the blood flow in the brain arteries.

## Transient ischaemic attack (TIA)

Blood supply to the brain is blocked temporarily. If the blockage clears, the blood supply starts again and the signs of stroke disappear. A TIA will have no lasting impact, making it different to a stroke. A TIA is a warning that you may have a stroke. Never ignore the signs of stroke, even if they disappear. Always call triple zero (000).

## Transoesophageal echocardiogram (TOE)

A tube-like device is passed down the throat into the oesophagus to get a clearer view of the heart muscles, valves and area around the heart.

## Verbal apraxia

Difficulty coordinating the muscles used for speech. Also called dyspraxia.

## Videofluoroscopy

X-ray to see if food or drink is going into your lungs when you swallow. Also called a modified barium swallow.

## Visual agnosia

Difficulty recognising familiar faces and objects.

## Stroke Foundation fact sheets

Your stroke team can give you copies. Visit [strokefoundation.org.au](http://strokefoundation.org.au)  
Call StrokeLine 1800 787 653.

Topic	Do I want to learn more about this topic?	Have I read this fact sheet?
Aged care homes		
Alcohol		
Communication		
Depression and anxiety		
Diet		
Driving		
Emotional and personality changes		
Fatigue		
Incontinence		
Medication		
Mobility and exercise		
Palliative care		
Pain		
Return to work		
Sex and relationships		
Supporting children after a family member's stroke		
Swallowing problems		
Thinking and perception		
Upper limb management		
Vision		



### How to get more involved

- 🕒 **Give time** – become a volunteer.
- 👛 **Raise funds** – donate or hold a fundraising event.
- 🗣️ **Speak up** – join our advocacy team.
- 🌱 **Leave a lasting legacy** – include a gift in your Will.
- ⊕ **Know your numbers** – check your health regularly.
- 📡 **Stay informed** – keep up-to-date and share our message.

### Contact us

- ☎️ **StrokeLine 1800 STROKE**  
(1800 787 653)
- 💻 [strokefoundation.org.au](http://strokefoundation.org.au)
- 📘 [/strokefoundation](https://www.facebook.com/strokefoundation)
- 🐦 [@strokefdn](https://twitter.com/strokefdn)
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