

About Stroke Foundation

Stroke Foundation is an Australian charity.

We work with survivors of stroke, families, health professionals and researchers to:

- Tell the community about signs of stroke.
- **>** Help people reduce their risk of stroke.
- > Help improve stroke treatment.
- **>** Help survivors of stroke and their families live a good life.
- > Support stroke research.
- > Raise money to keep doing our work.

Acknowledgement

Stroke Foundation respectfully acknowledges the Traditional Owners and Custodians of Country throughout Australia and acknowledges their continuing connection to land, water, sky and community.

We pay our respect to the peoples, cultures, and Elders past and present for they hold the memories, culture and hope of their peoples.

Thank you

Thank you to everyone who shared their story in this book. Thank you to the survivors of stroke, family members, carers and stroke health professionals who provided their expertise.

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Note: The full document is available at strokefoundation.org.au

About this book

This book is for survivors of stroke, families, carers and friends.

Most people don't know much about stroke. This book has the information you need. Stories from survivors, families and carers tell you about the road ahead.

Keep this book with you while you are in hospital. Take it with you when you go home. Take it to your GP and follow-up appointments.

You don't need to read the whole book.

Start by reading **What you need to know** on page 4.

Use the **Contents** on page 6 to find other information you need.

Your hospital team will fill in the **My stroke and recovery** pages with you. You and your family can write notes in this book.

If family members would like a printed copy:

- **>** Ask your hospital team.
- Ask StrokeLine. Call 1800 787 653. Email strokeline@strokefoundation.org.au

We have different versions of this book:

- > For Aboriginal and Torres Strait Islander people.
- **>** Easy to read.
- > Other languages.

Ask your hospital team or StrokeLine for a copy.

Are you a **young survivor**? We have information especially for survivors 18 – 65 years old, their families, carers and friends.



To see information for young survivors, point your phone or tablet camera on this code. Click the web address that appears.

What you need to know

- 1. A **stroke** is when blood cannot get to all parts of your brain. If this happens, your brain can be injured.
- 2. Always call triple zero (000) if you have any of the signs of stroke. If you have a stroke, treatment can help you. The faster you get treatment, the more brain can be saved. Even if you aren't sure, or the signs disappear, call triple zero (000).
- 3. While you're in hospital, a team of people will look after you. Your hospital team will arrange the **tests** and **treatment** you need. Some appointments may happen after you get home.
- 4. A stroke can **change** how you walk, move, swallow, think, talk and see.
- 5. In **rehabilitation**, you'll do exercises and activities to help with the changes after your stroke. Rehabilitation helps you be safe and get stronger. Family and friends can help you work on your rehabilitation goals.
- 6. It's common to feel very tired after a stroke this is called **fatigue**.

- 7. It's normal to feel **sad, worried or scared** after a stroke. You may also feel hopeful about getting better and grateful for your family and friends. Talk with your hospital team, family and friends about how you are feeling.
- 8. **Depression and anxiety** are common after a stroke. You can get support and treatment. These are things you can do that will help. Get to know the signs on page 32. Talk with your hospital team or GP.
- 9. After a stroke, you need to take **care of your health**. Your hospital team will talk with you about reducing your risk of another stroke. Most people need to take medicine for the rest of their life.
- 10. You can't drive for at least 4 weeks after a stroke. Commercial licence holders can't drive for at least 3 months. Your health professionals can assess your ability to drive safely.
- 11. Your hospital team will talk with you about **leaving hospital**. You need a discharge plan. Go see your GP within a week of leaving hospital.
- 12. Anyone can be a **carer**. Carers help a family member or friend with day-today living. Carer services can make life easier.



StrokeLine: information, advice and support

The StrokeLine team help survivors of stroke, families, carers and friends. The StrokeLine team are nursing and allied health professionals.

They take the time to listen. They can answer your questions.

They will:

- > Tell you about things that will help.
- **>** Help you solve problems.
- > Connect you to services.

StrokeLine is a free, confidential and practical service.

StrokeLine is open Monday to Friday, 9am to 5pm Australian Eastern Time.

StrokeLine is closed on Australian national public holidays.

Call 1800 787 653.

Email strokeline@strokefoundation.org.au

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 nurses, occupational therapists, physiotherapists, speech pathologists and social workers. Between us we have decades of stroke care experience. We know the system inside out.

You'll come away from your contact with StrokeLine with a plan that works for you. We also hope you'll know you're not alone. We're here for as long as you need us.

Kath, StrokeLine manager and physiotherapist



Contents

What you need to know	4
StrokeLine: information, advice and support	5

My stroke and recovery	8
My stroke	8
My hospital team	9
My stroke risk factors	10
My leaving hospital check list	12
My questions and goals	13

What is a stroke?	14
Signs of stroke	15–16
Tests	16
Treatment	18
Your hospital team	19
Working with your team	21
Young stroke	22
Having someone in hospital: information for family and carers	23

How will my stroke change me?	24
Arms, legs and muscles	26
Communicating	26
Swallowing	27
Thinking and personality	27
Fatigue	27
Touch and sensation	30

Sensory overload	30
Vision	30
Incontinence	30
Pain	30
Sex	30
Emotional lability	31
Feelings	31
Depression and anxiety	32
Relationships and family life	33
Driving	36
Work and study	37
Decision-making	37

Rehabilitation	38
Neuroplasticity	39
How much will I improve?	39
Get the most out of rehabilitation	40
Set goals	40
EnableMe: stroke recovery website	41

Reduce your risk of stroke	44
High blood pressure	44
High cholesterol	45
Type 2 diabetes	45
Atrial fibrillation	45
Other medical risk factors	48

Contents

Eat well	49
Move more	52
Maintain a healthy weight	53
Don't smoke	53
Avoid alcohol	53
Medicine after stroke	54
Get ready to leave hospital	55
Discharge planning	55

Get ready to leave hospital 55 Discharge planning 55 Your general practitioner (GP) 56 Get ready to care for someone: information for family and carers 56 Carer services 57

Get help at home	60
StrokeLine	60
Connect with other survivors, family members and carers	60
Problems to look out for	62
Get more rehabilitation	63
Disability and aged care services	63
Aids and equipment	63
Stroke fact sheets: more information	63
Money	64
Post-traumatic growth	64
Get help 24 hours a day, 7 days a week	65

Strokesaurus – medical words 68

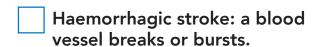
My stroke and recovery

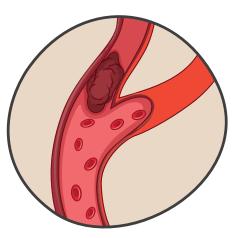
My stroke

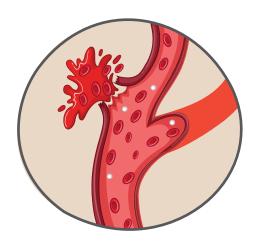
A stroke is when blood cannot get to all parts of your brain. If this happens, your brain can be injured.

Ask your hospital team to tick what type of stroke you had.

Ischaemic stroke: an artery is blocked.







Notes:	

My hospital team

Name	Contact details
Doctors	
Nurses	
Physiotherapist (physio)	
Occupational therapist (OT)	
Speech pathologist	
Dietitian	
Social worker	
Psychologist	
Neuropsychologist	
Allied health assistant	
Pharmacist	
Stroke care coordinator, discharge planner or key worker	
Aboriginal Liaison Officer	
Other	

My stroke risk factors

Ask your hospital team to fill this in with you.

RISK FACTOR	WHAT I NEED TO DO (Tick the things you need to do and add in other things that will help)	NOTES	FIND OUT MORE
High blood pressure	 Take medicine prescribed by your doctor. Ask your GP or pharmacist to check your blood pressure regularly. Eat well, move more and maintain a healthy weight. Don't have too much salt. 		Read page 44
High cholesterol	 Take medicine prescribed by your doctor. Get your GP to check your cholesterol regularly. Eat well, move more and maintain a healthy weight. Eat less saturated fat. Don't smoke. 		Read page 45
Type 2 diabetes	 Take medicine prescribed by your doctor. Check your blood sugar when you're supposed to. Eat well, move more and maintain a healthy weight. Don't smoke and avoid alcohol. 		Read page 45
Atrial fibrillation (AF)	 Report any potential symptoms to your hospital team – racing heart, palpitations, dizziness. Take medicine prescribed by your doctor. Eat well, move more and maintain a healthy weight. Don't smoke and avoid alcohol. 		Read page 45

RISK FACTOR (Tick if applies to you)	WHAT I NEED TO DO (Tick the things you need to do and add in other things that will help)	NOTES	FIND OUT MORE
Not eating well	 Eat more fresh food – vegetables, grains, fruit, lean meat, eggs, tofu, nuts, seeds and beans, milk, cheese and yoghurt. Eat less butter, cream, cooking margarine, coconut oil and palm oil, salt and sugar. Drink water. Ask your hospital team or GP how much water you should drink each day. 		Read page 49
Not moving enough	 Ask your hospital team about ways to move more that will work for you. Move as much as you can throughout your day. Be active for at least 30 minutes every day. Reduce the time you spend sitting or not moving. Break it up as much as you can. 		Read page 52
Unhealthy weight	 Ask your hospital team what a healthy weight is for you. Eat well, move more and avoid alcohol. See your GP regularly for help getting to a healthy weight. 		Read page 53
Smoking O	 Talk with your hospital team or GP about stopping smoking. Nicotine replacement therapy or a stop smoking medicine can help you quit successfully. Call Quitline on 13 78 48 or visit quit.org.au 		Read page 53
Avoid Alcohol	Talk with your hospital team or GP about alcohol and your risk of stroke.Get support to change your drinking.		Read page 53

My leaving hospital checklist

Fill in this in when you are getting ready to leave hospital. Ask your team about anything you're not sure about.

My stroke	 I know who to talk to if I'm worried about something to do with my stroke.
Medicine	 I know what medicines I need to take. I know the amount I need to take. I know how often I need to take my medicine. I have enough medicine to last until I see my GP.
Follow-up appointments	I know what 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 things safely.The people helping me know how to help me.
Changes to my home	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.
Risk factors	O I know how to control my stroke risk factors.
Signs of stroke	 I know the signs of stroke – Face. Arms. Speech. Time. I know to call triple zero (000) if I have any of the signs of stroke.

Appointment or service	Date and time	Contact details

My questions

Use this space to write down questions			
you want to ask your hospital team.			
My goals			
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0.00	v		
Use this space to write down:	You can use the goal setting tool on		
> What's most important to you.	EnableMe to set goals and break them		
	down into steps. Visit: enableme.org.au		
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> What you want to work on in rehabilitation.			
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What is a stroke?

A stroke is when blood can't get to all parts of your brain. If this happens, your brain can be injured.

Blood carries oxygen and nutrients for your brain cells.

Blood flows through your blood vessels. Blood vessels are like tubes or pipes. If blood can't get through, brain cells start to die and your brain can be injured.



Blood vessels include arteries and veins. Arteries carry blood from the heart to the brain and the rest of the body. Veins return blood to the heart.

My stroke

Ask your hospital team to tick what type of stroke you had on page 8.

Ischaemic stroke

An artery is **blocked** by a blood clot. Blood can't get through to all parts of the brain.

Ischaemic is said like this: is-key-mic.

There are different ways this can happen:

- A blood clot forms in an artery in the brain.
- A blood clot forms in the heart or blood vessels in the neck. It travels to an artery in the brain.
- Cholesterol plaque builds up in the artery wall. A blood clot forms.

Haemorrhagic stroke

A blood vessel **breaks or bursts**. Blood leaks into the brain. The leaking blood is like a bruise that injures the brain.

Haemorrhagic is said like this: hem-or-raj-ic.

There are two types of haemorrhagic stroke:

Intracerebral haemorrhage is bleeding in the brain.

Subarachnoid haemorrhage is bleeding on the surface of the brain.

Learn the F.A.S.T. signs of STROKE









If you see any of these signs

Act FAST call triple zero (000)



Signs of stroke

If you have a stroke, treatment can help you. The faster you get treatment, the more brain can be saved.

Always call triple zero (000) if you have any of the signs of stroke.

Even if you aren't sure, or the signs disappear, call triple zero (000).

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

There can be other signs, including:

- Numbness, clumsiness, weakness or paralysis. This can be in the face, arm or leg. It's usually on one side, but can be on both.
- Headache. It's usually severe and sudden.
- **>** Dizziness, especially head spins.
- > Loss of balance.
- > Unexplained fall.
- **)** Loss of vision in one or both eyes.
- > Difficulty swallowing.
- > Nausea or vomiting.

Share the F.A.S.T. message with family, friends and workmates.

StrokeLine can send you F.A.S.T. message cards.

Call 1800 787 653. Email strokeline@ strokefoundation.org.au

Tests

While you're in hospital, you'll have tests to find out:

- **>** What type of stroke you had.
- What part of your brain is injured and how badly.
- > What caused your stroke.
- > If it's safe for you to eat and drink.

There are some tests everyone should have. Other tests, only some people need. You may have some tests more than once.

Your hospital team will make sure you get the tests and treatment you need.

Brain scans and tests

Computerised tomography (CT) or magnetic resonance imaging (MRI)

These are scans that take pictures of your brain. Everyone should have a brain scan as soon as possible after arriving at hospital.

Brain scans confirm you had a stroke. They show:

- What type of stroke you had.
- > What part of your brain is injured.
- > How badly your brain is injured.

As part of your scans, you may need an injection of contrast dye. This shows more information about your brain and type of stroke.

Artery tests

Arteries in the neck carry blood to the brain. Tests can show if the arteries are narrowed or blocked.

You may have a **Carotid Doppler** ultrasound or a **CT angiogram**.

For a CT angiogram, contrast dye is injected and X-rays are taken to show the blockage. This is often done at the same time as your brain scan.

Heart tests

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

Electrocardiogram (ECG)

This test shows:

- > Problems with your heart rhythm.
- > Heart disease.

Everyone should have an ECG.

Electrodes are placed on your chest to record heart activity.

A Holter monitor is a wearable ECG. It measures your heart activity over a longer period.

Echocardiogram (ECHO)

This ultrasound test shows:

- > A blood clot in your heart.
- **>** A patent foramen ovale in your heart.
- If the chambers of your heart are enlarged.

Transoesophageal echocardiogram (TOE)

This test shows problems with the heart muscles, valves and the area around the heart.

A tube with an ultrasound scanner is passed down the throat into the oesophagus (your food pipe). The oesophagus passes near the heart.

Blood tests

Blood tests can help find health problems that may have caused your stroke. These include:

- > The time it takes your blood to clot.
- > Kidney function.
- > Blood sugar levels.
- > Salt levels.
- > Blood cell count.
- > Cholesterol levels.
- > Iron levels.

Swallowing test

Your team will test how well you can swallow before you eat or drink. Eating or drinking when you can't swallow properly can make you sick.

Some tests may happen after you get home. Make sure you go to all your appointments.

Talk with your GP if:

- > You're not sure of the details.
- > You need help getting to appointments.

Find out more about the health conditions these tests can reveal. Read the Reduce your risk of stroke section, starting on page 44.

Treatment

Your hospital team will talk with you and your family about what treatment is right for you.

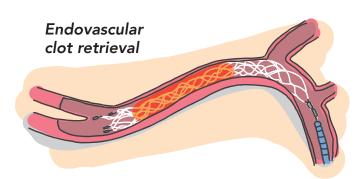
Ischaemic stroke

Your hospital team may give you **medicine** to clear the blocked artery. The medicine is given through an injection in your arm. This is called thrombolysis, or clot busting.

You may have a **procedure** to unblock the artery.

Your doctor puts a tube into an artery in your arm or leg. The tube is fed into your brain. Contrast dye is injected and X-rays are taken to show the blockage. This part of the procedure is called an angiogram.

A small device is then used to pull out the clot. This is called thrombectomy or endovascular clot retrieval (ECR).



Aspirin or other blood-thinning medicine reduces the risk of another stroke.

A **carotid endarterectomy** is surgery for severely narrowed carotid arteries. These arteries in your neck carry blood to the brain. The surgery removes plaque to improve blood flow and reduce your risk of another stroke.

Haemorrhagic stroke

Your team may give you medicine to:

- Slow down or stop the bleeding in your brain.
- > Control your blood pressure.

You may need an **operation** to:

- > Remove blood from your brain.
- > Fix a blood vessel in your brain.
- > Relieve pressure in your brain.

Note	9:		

Your hospital team

After a stroke, everyone should have a hospital stay.

Everyone should be treated in a stroke unit. Stroke units have teams that specialise in stroke. Not all hospitals have stroke units, so you may need to be moved to another hospital.

Your hospital team will:

- **>** Organise tests and assessments.
- > Plan and deliver your treatment, care and rehabilitation.
- > Plan for you to leave hospital.

The information below is a general guide. Different hospitals have different kinds of staffing and names for staff.

Doctors

Doctors look after your medical care.

Consultants lead your medical care. They are specialists – neurologists, rehabilitation physicians or geriatricians. You'll see consultants in ward rounds and meetings.

Registrars are the stroke unit's senior doctors. They have specialist training.

Residents look after patients in the stroke unit. They are the doctors you'll see most.

Interns are in their first year of working in a hospital.

Nurses

Nurses look after your treatment and care.



The nurse unit manager (NUM) runs the ward, helped by the associate nurse unit manager (ANUM).

Clinical nurse consultants (CNC) are highly trained nurses with specialist stroke training.

Registered nurses observe patient health, give medicine and do minor procedures. They are the nurses you'll see the most.

Enrolled nurses provide general nursing care.



Allied health

Allied health professionals assess the impact of your stroke. They plan and deliver your rehabilitation with you.

You will see the allied health professionals who can help with the changes from your stroke.



Physiotherapists help you sit, stand, balance, walk and move. They help reduce your risk of falls.



Occupational therapists (OT) help you do the things you need to do every day.



Speech pathologists help with communication – how you talk, understand, read and write. They also help with swallowing.



Dietitians make sure you have the right food and drink. They talk with you about healthy eating.



Social workers ask how you and your family are going. They know what practical and emotional help is available.



Psychologists help with how you are feeling, especially if you are sad, down or worried.

Neuropsychologists help with concentration, memory, judgement, fatigue, mood and behaviour changes.

Allied health assistants (AHA) work under the supervision of allied health professionals. An AHA may help you with exercising and practising.

Other team members

Pharmacists make sure you have the medicines you need. They talk with you about your medicines.

Some teams have people who keep an eye on everything while you are in hospital. They talk with you about what you need and make a plan with you. They can be called:

- > Stroke care coordinator.
- Nurse navigator.
- Discharge planner.
- > Key worker.



Aboriginal Liaison Officers can help Aboriginal and Torres Strait Islander patients and families.

Working with your team

After a stroke, good teamwork makes for a better experience for everyone. Survivors of stroke, families, carers and health professionals are all part of the team.



Ask questions and share information

Talk with your team about:

- **)** How the stroke has impacted you.
- > Treatment, care and rehabilitation.
- > What changes you can expect over time.
- > What problems to look out for.
- > How our health system works.

Your team is your best source of information. Ask lots of questions.

Your team will also ask you questions. It can feel repetitive, but it all adds to the team's knowledge. Let your team know anything that might help them deliver good treatment and care. Talk about any concerns. Let them know when you don't understand something.

After talking with your team, you should feel like there's been a good exchange of information. You should know more about:

- > What's happening.
- > What the next steps are.
- > What your team will do.
- > What you need to do.

Keep notes

Take notes when people tell you things. You can:

- > Write things in this book.
- Use an app to keep notes on your phone or tablet.
- Use 'convert voice to text' on your phone or tablet.
- > Ask family and friends to help.

Keep a list of questions you want to ask. There's a spot on page 13 to write down your questions. You can also use your phone or tablet.



66

Information is incredibly important. You need good information to make informed decisions. Access to good information makes a difference to your outcomes throughout your recovery.

After a stroke, you need to go from beginner to expert – fast.

Adrian, survivor of stroke

Family meetings

A family meeting brings together survivors, family and carers, and the hospital team. It's a chance to share information, ask questions, talk about any concerns, and discuss next steps.

Make the most of a family meeting:

- Ask for an interpreter if anyone needs one.
- Make sure everyone knows about the meeting.
- Get people to phone in if they can't be there in person.
- Write down your questions and things you want to tell the team.
- **)** Make sure someone's taking notes.

Give feedback

Sometimes there are things you're not happy with. You can talk to:

- > the nurse unit manager.
- the hospital's patient advocate or consumer liaison officer.

Talk with StrokeLine

The StrokeLine team can give you information, advice and support. If you need to talk something through, contact StrokeLine.

Call **1800 787 653**. Email **strokeline@ strokefoundation.org.au**

Young stroke

Are you a younger survivor?

We have information especially for survivors 18 – 65 years old, their families, carers and friends.

young.strokefoundation.org.au is a starting place to find information about stroke and recovery. A safe place to feel less alone.

It's a place to hear survivors, family and friends talk about life after stroke, what they've learnt and what helps. Find out how to connect with others who get it.



To see information for young survivors, point your phone or tablet camera on this code. Click on the web address that appears.



You don't have to do this alone!

When I was 24, I survived a major stroke. I woke up in ICU and discovered I'd lost the ability to walk, talk, swallow,

see, and breathe on my own. I also lost my job and felt like I'd lost my identity.

I felt disempowered, disoriented, isolated and alone – so, I started connecting with other young survivors.

I quickly realised that we all share very relatable stories; loss, grief, new identities forming and celebration.

Over time, I reached out to other survivors and started creating a safe space for empathy, empowerment and connection.

At genyus network, you can connect with other survivors just like you, hear their stories and share your own.

We're online – we have private forums, topic discussion threads and social meetups.

Join us at genyusnetwork.com

Caleb Rixon, survivor of stroke

Having someone in hospital: information for family and carers

While someone's in hospital, they need a lot of help from family, carers and friends. You may:

- > Spend lots of time at the hospital.
- Talk with the hospital team about your family member. If they're very unwell, you may make decisions for them.
- **>** Be on the phone letting family and friends know what's going on.
- > Keep everything going at home.

All the while you may be upset or worried.

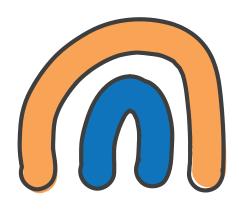
After a while, you will need to slow down and take time to rest. Ask family and friends to visit at the hospital so you can take a break. If people offer to help, say yes. If people want to help but aren't sure how, let them know what they can do.

Family and friends can help with:

- > Driving you places.
- **>** Sharing updates with family, friends and workmates.
- Looking after kids, family members and pets.
- > Doing chores and errands.

The hospital social worker can help with any problems you are having. They know what support is available.

Being in hospital is hard. Talk with your hospital team if your family member wants to leave hospital and head home.



How will my stroke change me?

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

A stroke can change how you walk, move, swallow, think, talk and see.

Different parts of the brain control different things. The brain has two sides – the left and right hemispheres. The left hemisphere controls most functions on the right side of the body. The right hemisphere controls most of the left side of the body.

The brain is divided into areas. The areas are called lobes. Each lobe controls different things.

How your stroke changes you depends on:

- > Which part of your brain was injured.
- > How badly it was injured.

This section is a quick overview of what can change after a stroke. Our **fact sheets** provide more information about what to expect and what you can do.

To get our fact sheets:

- > Ask your hospital team.
- Call StrokeLine 1800 787 653. Email strokeline@strokefoundation.org.au



To see our fact sheets, point your phone or tablet camera on this code. Click on the web address that appears.

Areas of the brain

Parietal lobe

- Touch, pain and feeling hot or cold
- Feeling where your body/limbs are without needing to look
- Calculation and writing

Occipital lobe

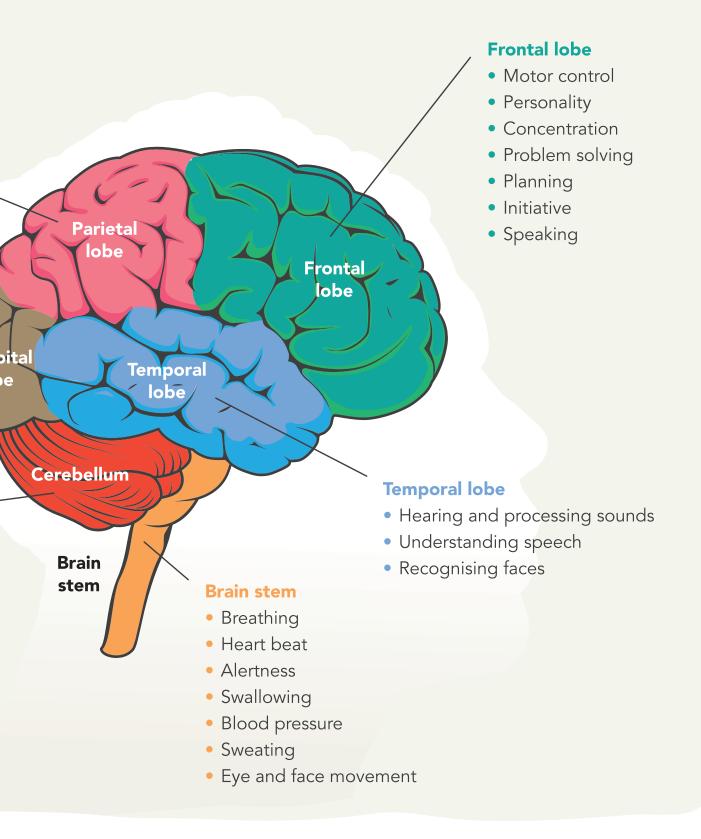
Vision

Cerebellum

- Balance
- Control of movement

Occi

- Posture
- Fine motor skills



Arms, legs and muscles

Your arms, legs and hands may not work like they used to. This can change how you sit, stand, move, balance, walk or move your arm. You may be at risk of falling.

Your muscles may be weak and floppy. Your brain may have trouble getting them to move.

Your muscles may feel stiff and tight. They resist movement. This is called muscle spasticity.

More information:

- Movement and exercise fact sheet
- O Shoulder, arm and hand fact sheet
- O Muscle spasticity fact sheet



Communicating

Stroke can change how you talk, understand, read and write. 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.
- You have trouble reading and writing.

All this is called aphasia.

If the muscles you use to talk don't work properly, your speech will be slurred. This is called **dysarthria**.

Communication difficulties can make life hard. If you're feeling sad, down or worried, let your hospital team, family and friends know.

More information:

Communication fact sheet

Family and friends can help you communicate. It helps if they:

- > Use short, clear sentences.
- > Be patient and give you time.
- Ask questions that can be answered yes or no.
- Have a picture or a key word you can you point to.
- Use gestures and facial expressions to support what they're saying.
- Include you in conversations.
- > Check you understand.
- Not worry about swearing, nonsense or repetitive words.

Swallowing

A stroke can affect the way you move food around in your mouth and how well you can swallow. This is called **dysphagia**.

Dysphagia can cause problems with eating and drinking. Food or drink might go down the wrong way and get into your lungs. This can make you very sick.

Your speech pathologist will make sure you are safe. They may give you exercises to improve your swallowing.

More information:

Swallowing fact sheet

Thinking and personality

Your thinking can change. It may be hard to:

- > Pay attention.
- > Figure out how to do things.
- > Remember things that just happened.

Your personality can change too. You may find you:

- > Don't feel like doing things.
- > Get annoyed easily.
- > Do things without thinking it through.
- > Say or do things that seem a bit strange.

More information:

- Thinking and perception fact sheet
- Personality and behaviour fact sheet

Fatigue

Fatigue is a feeling of weariness, tiredness or lack of energy. It's a persistent feeling that can get worse when you're active.

People with fatigue often describe having brain fog. They talk about hitting a wall and having to stop and rest.

About half of all survivors of stroke experience fatigue. It can affect anyone. It usually starts in the first few weeks after a stroke.

Everyone's level of fatigue will be different. Fatigue can improve with time but there's no way to know how much it will improve or how long it will take.

More information:

O Fatigue fact sheet



I would sleep in until 9 o'clock in the morning. I'd work for a few hours, and by 12 o'clock I just could not function. It was like my brain just went 'You know what, that's enough.'

I can still do the things I used to do. They just make me more tired. And so, I've got to be conscious of managing my energy.

You need to understand what gives you energy and what takes your energy away.

And you need to be really focused on doing the former and not the latter.

Lisa, survivor of stroke



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 the ones that came out. I couldn't trust what I was saying.

I made good progress to begin with. Before long I could get by, despite some mistakes. Then 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 dropped, 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 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 interfered with my recovery. Words like 'should' and 'hard' have an energy associated with them. 'Should' has the energy of guilt. 'Hard' is immovable like concrete. I prefer the word 'challenging' as it suggests the chance of achieving things.

Using positive words empowered and moved me forward. Using words like 'could' or 'would' gave me possibilities.

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

Touch and sensation

Parts of your body may feel touch less or be numb. You can also feel touch more.

You may feel hot and cold sensations less. You may have pins and needles, tingling or other strange sensations.

More information:

Thinking and perception fact sheet

Sensory overload

Your brain may not filter out irrelevant sensory information. You may have trouble with:

- > Busy, noisy or new places.
- Bright lights and loud noises.
- Social situations with lots of talking, music and touching.

Vision

You may have a blind spot. It's like people and things in the missing part aren't there.

You may see double. Your eyes may move all the time. Your eyes may be more sensitive to light.

More information:

Vision fact sheet

Incontinence

Incontinence is when you can't control your bladder and bowel. You may have trouble:

- Xnowing you need to go to the toilet.
- > Getting there in time.
- > Asking for help to go.

More information:

Incontinence fact sheet

Pain

You may feel pain because:

- > A part of your body is injured.
- **>** Your muscles are stiff and tight.
- Changes in your brain make you feel pain even if you're not injured.

More information:

O Pain fact sheet

Sex

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

Having sex doesn't cause strokes. For many people, getting back to having sex is part of getting better. Talk with your partner when you're ready. You may have trouble with:

- > How well you can move.
- > Muscle weakness, stiffness or tightness.
- > Pain or incontinence.
- > How it feels when someone touches you.
- > Feeling sad, worried or tired.

Some medical problems and medicines change how your body responds during sex.

You can talk to your team about sex. Health professionals are used to talking about sex. They can talk with you about doing things differently. They can let you know ways to make sex easier and more enjoyable.

More information:

O Sex and intimacy fact sheet





For me, sex was important. I needed to know everything still worked. I wanted that connection with my husband. I think I wanted to prove I was still me, and that we would continue as normal as a couple.

We've discovered things don't all work as they did pre-stroke. This has affected us in different ways. I experience the physical effects whilst Nick gets the psychological ones.

Each survivor's experience of stroke is different, and this includes your intimate relationships. The important thing is to communicate with each other and seek help if needed.

Toni, survivor of stroke

Emotional lability

You may laugh or cry for no good reason. Emotional responses may not seem to make much sense – you may laugh at something sad. Your responses may be out of proportion.

More information:

 Emotional and personality changes fact sheet

Feelings

You may be:

- Worried about why you had a stroke.
- Unhappy about being in hospital and away from home.
- Sad or embarrassed about the change from how you were before.
- Grateful to be alive and for your family and friends.
- Hopeful about getting better.
- > Scared about having another stroke.

Stroke is a sudden, serious and often life-changing experience. While these feelings are all normal, it can feel overwhelming.

Talk with your team, family and friends about how you are feeling. Therapy sessions with a mental health professional can help.

Looking after yourself will also help. Eat healthy food and move as much as you can. Get into activities you enjoy. Spend time with people who make you feel good.

Depression and anxiety

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

These are signs of depression. You may have depression if you experience some of these, on most days, for more than two weeks.

- > Feel sad or down.
- Lose interest in things you enjoy.
- > Feel irritable, overwhelmed, empty or numb.
- > Feeling tired a lot of the time.
- > Find it hard to concentrate.
- Have trouble sleeping or sleep more than usual.

These are signs of anxiety. You may have anxiety if you experience some of these, on most days, for more than two weeks.

- > Feel very worried or anxious most of the time.
- > Find it hard to calm down.
- > Feel tired a lot of the time.
- > Have trouble concentrating.
- > Find your mind goes blank.
- > Have tense muscles.
- Have trouble getting to sleep and staying asleep.

You can get support and treatment for depression and anxiety. There are things you can do that will help.

Talk with your hospital team or GP if you think you may have depression or anxiety. Talk with family and friends too.

More information:

O Depression and anxiety fact sheet

Relationships and family life

Stroke can have a big impact on relationships and families.

The stroke creates a crisis. The survivor is in hospital, away from home. There are changes to roles, responsibilities, routines and plans. There can be work and money pressures.

How we feel about ourselves and others can change. With everything going on, it can be hard to look after ourselves and each other.

Within families, there can be different ways of approaching things. There can be different expectations about what should happen.

Changes after stroke can also impact relationships. If you are having trouble communicating, it can be hard to:

- > Chat, share ideas and make jokes.
- > Talk about feelings and comfort each other.
- > Make decisions and plans.

Even things like changes to touch and sensation can have an impact. A survivor of stroke may not know if someone has touched them affectionately as they walk by.

Fatigue and sensory overload can make being at family events difficult.

Every survivor, partner and family member experiences these changes in their own way.

Focus on what matters most to you. Keep communicating with each other. Build new routines. Do things you enjoy together.

Therapy with a mental health professional can help. You can have sessions on your own, with your partner or as a family.

More information:

O Supporting children after a family member's stroke fact sheet





Shazia's story

I was a busy mum of two young kids, a wife, and a full-time worker. I tried to do everything. I juggled looking after my family and my career. I grew up in a simple household, I was quiet, and I kept a lot of things to myself.

My stroke experience is a mix of loss and gain.

I have lost strength and sensation on my right side. I struggle to write, and my speech gets slurred when I am tired.

I gained the courage to speak up and to focus on wellbeing. I cannot do everything, so I prioritise the most important things. I learned how to say no and how to ask for help.

I continue to look after my family but now I know to take time for self-care. This includes empowering my children so they can help at home and do things for themselves.

I encourage other survivors of stroke to speak up. Ask for help when you need it. Remember, you are your own best advocate.

Driving

Driving is a complex task. You need good vision, movement and thinking. Stroke can affect these abilities.

You must not drive a private vehicle for at least 4 weeks after a stroke. Commercial licence holders must not drive for at least 3 months. Your non-driving period only ends when a doctor clears you to drive.

You must tell the state driver licensing authority you have had a stroke. They can give you information about driving and stroke.

If getting back to driving is important to you, let your hospital team know. It can be a rehabilitation goal.

Your team will talk to you about how your stroke has affected your vision, movement and thinking.

They will explain the likely impact on your driving. They will explain what needs to happen next.

Your health professionals can assess your ability to drive and provide reports for the licensing authority if needed. This may happen after you leave hospital. State licensing authorities can then make decisions about your driver's licence.

If you want to get back to driving, read the Driving fact sheet.

You will need advice and support. Your health professionals, the state licensing authority and StrokeLine can help.

Call StrokeLine 1800 787 653. Email strokeline@strokefoundation.org.au

More information:

Driving fact sheet

Not being able to drive can make life hard. It's common to experience grief and loss. Get advice and support from StrokeLine.

Notes:		

Work and study

Talk with your team about your work or study. You may need:

- > Changes to your job.
- Changes to the hours you work or your study load.
- > Different ways of doing things.
- > Aids and equipment.

Fatigue can last longer than you expect. It can be good to work shorter hours or do fewer subjects when you first go back.

Your team can talk with your employer, school or uni about your stroke and what you need. Ask them what help is available and what to do if problems come up.

More information:

Return to work fact sheet

Decision-making

All adults have the right to make their own decisions. If someone becomes unable to make reasoned decisions because of illness or disability, there are laws about how decisions can be made for them. Your social worker can provide advice about decision making.

Person responsible. If you are too unwell to make decisions about your medical treatment, your doctor can ask someone else to make a decision. There are laws for deciding who this person is.

Guardianship and administration.

A guardian makes lifestyle or personal decisions. An administrator makes financial decisions. There is a legal body in each state that can appoint these decisionmakers if needed.

Enduring powers of attorney appoint someone to make decisions for you if you can no longer make decisions for yourself. You can only make an enduring power of attorney while you are able to fully understand:

- > The nature and effect of the document you are completing.
- > The nature and extent of your affairs.

Advance care directive. This document outlines your wishes if you become very unwell.

Rehabilitation

Rehabilitation is where you work on things that have changed since your stroke. It helps you be safe and get stronger. Your hospital team will begin working on your rehabilitation as soon you are well enough.

Rehabilitation is called rehab for short. In rehab you'll do a lot of exercises. You'll practise tasks over and over.

Everything you do is a part of rehab. Getting dressed, making a drink and a meal, and having a session with a psychologist are all part of it.

You may have:

- > Inpatient rehabilitation at a hospital.
- In-home rehabilitation your rehabilitation team comes to your house.
- Community or outpatient rehabilitation

 you visit a centre for rehab but live
 at home.

It depends on what's best for you and what's available in your area.

Your team will help work out what has changed for you. You'll have tests and assessments. Tell them about any changes you've noticed since your stroke. You'll work with your team to set rehab goals.

Your team will help you:

Be safe. You may need:

- > Someone with you when you move or walk.
- > Changes to what you eat and drink.
- > A walking stick or frame.

Manage the changes. You may need:

- To position your head, shoulder, arm and hand in a particular way.
- To use your phone, calendar or pictures to help you remember.
- Continence products.
- Special equipment.
- > Medicine.

Do things differently. You may need:

- New ways and tools to communicate.
- > A quiet place to concentrate.
- To break tasks down into steps and take your time.
- > To talk with family and friends about what's changed and let them help you.

Improve. You'll need to:

- Do exercises and practise tasks over and over.
- Move as much as you can throughout the day.

What you need, and what will work best for you, is unique to you.

If the changes you're experiencing since your stroke are hard to cope with, let your team know you're struggling. They can talk with you and arrange the right support.



Neuroplasticity

Neuroplasticity is your brain's ability to change and adapt.

After a stroke, pathways in the brain can change. Uninjured parts of the brain can take over the jobs of injured areas.

This helps you get better, but it takes a lot of work to help the brain build new pathways. You need to:

- Repeat a movement or task over and over. Your team will tell you the number of repetitions to aim for.
- Do the movement or task at the right level of difficulty. You should be able to do it accurately, but it also needs to be challenging.

Simply put: **repetition**, **accuracy** and **challenge** are the keys to neuroplasticity.

Neuroplasticity is happening as you work on your rehabilitation and recovery. You may improve more quickly in the first few months, but you can continue to improve for years. Sometimes it might feel like you aren't making progress – like you've plateaued. Talk with your team, review your goals and keep working on it.

How much will I improve?

It's hard to know how much you will improve. Your stroke team may instead talk about what is likely to happen. Your recovery may depend on:

- The area of the brain that was injured.
- **>** How much it was injured.
- > How rehabilitation is going.

Everyone's recovery is different. It takes work and time. Not knowing how much you will improve is frustrating. Focusing on your rehabilitation helps. Setting realistic goals and celebrating your achievements also helps.



66

My advice. Try. Try. Try. Wait and see, and yes. Amazing.

Ben, survivor of stroke and person with aphasia

Everyone says to you that survivors will only make gains in the first six months, and that's just complete nonsense. Ben continues to make gains on a weekly basis.

Gabby, Ben's partner

Get the most out of rehabilitation

Ask questions. If you don't understand what you are doing or why, ask your team. They're there to help. Build a good relationship with them.

Set goals. Start by asking yourself, 'What do I want to do? Where do I want to be in a week, a month or a year?'

Your team can help you get there. They'll help you:

- Pick some things you can achieve quickly and some that will take longer.
- > Set goals that are realistic and achievable.
- > Break goals down into steps.

Write down what matters most to you on page 13. Show your team.

Don't just focus on the physical. All areas are important to work on. This might include your emotions and thinking or managing finances, work and study.

Involve family and friends. Spend time catching up, then ask people to help with your exercises. They can help keep you motivated, hold you accountable and cheer you on.

Rest and relax. Rehab is hard work. Take breaks when you need to. Try to get good sleep. Make time for things you enjoy. When the time's right, talk with your team about day leave and have a change of scene.

It's normal to feel frustrated or down.

Sometimes it takes longer than you think it will. You may grieve for the way things were. Talk with your team, family and friends about it.

Advocate. If you think you should be getting more rehab or something isn't working, speak up. Get a family member or friend to support you, or to talk with the team on your behalf.

Connect with other survivors. Seeing how far others have progressed can provide hope. It can show you what's possible if you keep working at it.

Keep going. Stroke recovery is a lifelong journey. It's not a race. Sometimes it feels like you're not getting better. You will have good and bad days. Don't give up.

Celebrate. Take a photo, keep a journal or make a video to keep track of how far you've come. Share with friends and family.



I make the most of rehab by going. I still am in rehab today. It's about getting the reps in. A little and often is worth way more to me than going bananas twice a week. Consistency beats intensity any day of the week.

Everyone's stroke journey is just so different. So it really is educated guesses, trial and error. And I think you need to need to get your head around that. It's a long journey. I think knowing that, being told that in terms we understood, may have helped set our expectations a little bit.

Advocacy is so critical. I mean, I didn't know up from down. I was pretty vulnerable. I was very lucky I had my wife to advocate for me.

Paul, survivor of stroke



Having goals to work towards was very useful, because they gave me a clear vision.

When the physio came for the first time to my room in the hospital, they asked me what my goal was. I said, 'I want to be able to play

soccer again.' The first thing I had to do was to learn to stand up. Then I had to learn to walk.

And the last thing I learned to do was run.

Nicole, survivor of stroke

EnableMe: stroke recovery website

EnableMe is a website for survivors of stroke, families, carers and friends. EnableMe can help with your stroke recovery.

Get the information you need:

- > Fact sheets.
- > Podcasts.
- > Videos.
- > Blogs and forums.
- > Strokeasaurus medical terms.

Connect with people who get it:

- > Start a conversation.
- > Ask questions and share advice.
- > Tell your story.
- > Celebrate your recovery.

Connect with StrokeLine:

Visit the Community section and use **Ask a health professional** to get your questions answered by StrokeLine.

Registering on EnableMe is easy – it only takes a few minutes. Once you're registered, you can post comments, blogs and forums. You can also connect with the StrokeLine team. You can use the accessibility features to make EnableMe suit you.



To check out EnableMe, point your phone or tablet camera on this code. Click on the web address that appears.

Need help to get started? Contact Strokel ine.

Call **1800 787 653**. Email **strokeline@ strokefoundation.org.au**



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. EnableMe is wonderful.

My moods were up and down and my reactions to things felt out of proportion. I was bewildered as I'd never felt like that before my stroke. I joined EnableMe and I discovered my emotional changes are commonly experienced after stroke. That's helped me immensely.

Jenny, survivor of stroke





Domenico's story

I had a big stroke. The doctors told my wife Liz that I had a significant bleed that would leave me disabled. At one point, they said I would not be able to come home. I proved them wrong.

I had to relearn everything. Rehabilitation was difficult and exhausting. We had our fair share of crying, becoming frustrated and feeling like we were fighting a constant battle.

But I was determined to get home and to recover. I wanted to get back to my life and all the things I found meaningful. That desire was bigger than my stroke and I had a great team supporting me.

Liz, my son Cameron and my daughter-inlaw Alana were the biggest supports. Liz talked to different people at the hospital. She also spoke with other patients and families. We received a lot of help from the rehabilitation team. Cameron reached out to Stroke Foundation. Eventually, support from the National Disability Insurance Scheme came through.

Five years have passed, and I continue to work on my goals. My latest goal is to take my grandson to the park. We try to schedule things to balance appointments and activities with adequate rest. Some days are hard, but we keep going.

To this day, I believe the love of my life saved me. And I keep going to be with the people I love.

Reduce your risk of stroke

Looking after your health will help reduce your risk of having another stroke.

Risk factors are things that can cause a stroke or make it more likely to happen. They are different for everyone.

Your team will let you know what you need to do to keep your risk factors under control.

There are some stroke risk factors you cannot do anything about – being older, being male, a family history or already having had a stroke. But everyone can take action to reduce their risk.

Doing these things will make a big difference:

- Work with your doctor to manage your medical risk factors.
- Eat well, move more and maintain a healthy weight.
- **>** Don't smoke, and avoid alcohol.
- Go to all your follow-up appointments and see your GP regularly.
- > Take medication prescribed by your doctor.

High blood pressure

High blood pressure can damage the walls of blood vessels, and it can lead to heart problems. It can cause clots or plaques to break off and block an artery in the brain.

Normal blood pressure is around 120/80. If your blood pressure is over 140/90 a lot of the time, it's too high.

Keep your blood pressure under control:

- **>** Take medicine prescribed by your doctor.
- Ask your doctor or pharmacist to check your blood pressure regularly. You can buy a monitor and check it yourself.
- > Eat well, move more and maintain a healthy weight.
- Don't have too much salt. Read page 49 to find out more.
- **>** Don't smoke, and avoid alcohol.



High cholesterol

Cholesterol can build up in plaques on the walls of arteries, narrowing the artery and leading to a clot.

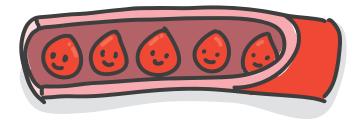
There are two types of cholesterol:

- Low density lipoprotein (LDL) is the bad 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 good cholesterol that removes other cholesterol from the blood stream. The more HDL, the lower your risk.

High total cholesterol is 5.5 mmol/L or more. However, there are different kinds of cholesterol that are measured in blood tests, and what are good levels for you depends on your other risk factors. Your doctor will tell you what levels to aim for.

Keep your cholesterol under control:

- **>** Take medicine prescribed by your doctor.
- Ask your doctor to check your cholesterol regularly.



- **>** Eat well, move more and maintain a healthy weight.
- > Eat less saturated fat. Read page 49 to find out more.
- Don't smoke.

Type 2 diabetes

Type 2 diabetes affects the body's ability to absorb glucose, which is a kind of sugar. It can lead to fatty deposits or clots in blood vessels.

Keep your diabetes under control:

- Take medicine prescribed by your doctor.
- Check your blood glucose when you're supposed to.
- Eat well, move more and maintain a healthy weight.
- **>** Don't smoke, and avoid alcohol.

Atrial fibrillation

Atrial fibrillation (AF) is an irregular heartbeat. One of the smaller heart chambers doesn't coordinate the pumping of blood properly. Blood stagnates and clots can form. These clots can then travel to the brain.

Keep your AF under control:

- Take medicine prescribed by your doctor.
- **>** Eat well, move more and maintain a healthy weight.
- **>** Don't smoke, and avoid alcohol.



Joe's story

I had my first stroke when I was in my early 50s, in a supermarket of all places.

I was lucky that my friend had taught me about the signs of stroke. I sat down on the floor and told my workmate who was with me to call triple zero (000). I was taken to hospital quickly, which saved me from further damage.

I've had a few strokes. Each felt very different. Sometimes it was the arm, another time I couldn't swallow, another time I vomited. My fourth stroke felt like I was on a rocky boat out at sea.

Looking back, there is always good and bad in life after stroke. It has been a hard road to recovery at times. After my first stroke I lost a lot of my independence and positivity for around six months. I needed help to walk, I became quite depressed and had some very dark days.

I kept thinking 'Am I ever going to work again? Am I going to have another stroke? Is the next one going to be worse than the one before? Will I survive it?' This worry caused a lack of sleep, which contributed to my depression.

I tried really hard to pull myself out of it, always reminding myself there was someone else out there with it worse than me. I quit smoking and drinking which really helped me get healthy and back on track. With help from my doctor and family and friends I have been a sober non-smoker now for more than five years.

I've given a few talks about my stroke experience to the community to spread awareness of the signs. When people ask for advice, I always say:

- Quit smoking, talk with your doctor about alcohol and keep your stress levels down.
- Have your health check-ups, listen to your doctors, and take your medication.
- **>** Ask for help. It is always available.

People are there to support you because they love you. If they didn't love you, they wouldn't be there. That's a big thing to remember.

Joe is a survivor of stroke and a proud Kooma man.

Other medical risk factors

Heart conditions including heart disease and patent foramen ovale (PFO). A PFO is a small hole between the two sides of the heart. Clots that form in veins can cross to arteries that supply blood to the brain.

Blood vessel problems including:

- Aneurysm a thin or weak spot in a blood vessel.
- Arteriovenous malformation (AVM)tangled blood vessels in the brain.
- Cavernous malformation tightly packed, small blood vessels with thin walls.
- Atherosclerosis build up of cholesterol plaques in arteries, often due to high blood pressure, cholesterol or diabetes.

Blood disorders including essential thrombocytosis, polycythaemia vera, antiphospholipid syndrome, and sickle cell anaemia

Genetic disorders including CADASIL, Ehlers-Danlos syndrome and fibromuscular dysplasia.

Cerebral vasculitis can inflame and narrow the walls of blood vessels.

Cerebral amyloid angiopathy (CAA) damages blood vessels in the brain.

An injury to the head or neck.

Infections including bacterial heart infections and COVID-19.

Pregnancy can increase blood pressure, especially with pre-eclampsia and eclampsia, and it can also cause gestational diabetes.

Oral contraception, particularly pills containing a higher dose of oestrogen.

Hormone replacement therapy slightly increases your risk of stroke.

Blood-thinning medicines reduce your chance of an ischaemic stroke but can increase your risk of a haemorrhagic stroke.

Amphetamine and cocaine can increase your risk of stroke.

Sometimes, despite testing, a cause can't found. This is called a cryptogenic stroke.

If the cause of your stroke is unknown, it's important to:

- > Talk with your doctor about what they have done to find the cause.
- > Go to all your follow-up appointments.
- Take the medicines your doctor prescribes.
- Eat well, move more and maintain a healthy weight.
- **>** Don't smoke, and avoid alcohol.

Eat well

Not eating well can cause:

- > High blood pressure.
- > High cholesterol.
- > Type 2 diabetes.
- Heart disease.

Get into fresh food. Eat meals you prepare at home. Eat more:

Vegetables. Fresh, frozen and tinned vegetables are all good.

Grains. Wheat, oats, rice, rye, barley, millet, quinoa and corn. Grain foods include bread, breakfast cereals, rice and pasta. Wholemeal, brown, multigrain and high fibre are best.

Fruit. Fresh, whole fruit is best. Frozen fruit is good too.

Lean meat, eggs, tofu, nuts, seeds and beans. If you eat meat, eat lean beef, chicken and fish. Eat unsalted nuts and seeds. Split peas, lentils, chickpeas and low-salt baked beans are good too.

Milk, cheese and yoghurt. Low fat is best. Fresh, long-life and powdered milk are all good.

Water. This is the best drink. Ask your hospital team or GP how much water your should drink each day.

Healthy fats and oils. There are different kinds of fats, and some are healthier than others. Use sunflower, canola and olive oil. Try nut butter or avocado.

Fat less:

Butter, cream, cooking margarine, coconut and palm oil.

Stay away from takeaway food like pies, hamburgers, pizza and chips. Same with biscuits, cakes and potato chips.

The fat in all these foods is called **saturated fat**. Too much of this fat can give you high cholesterol.

Salt. Too much salt can give you high blood pressure. Have less than four grams of salt a day. This is about three-quarters of a teaspoon. It's equivalent to 1600 milligrams of sodium.

Packaged food already has salt in it. The more fresh food you eat, the less salt you'll get. Don't add salt when you cook or when you eat. After a while you won't miss the salt.

Sugar. Too much sugar can damage your arteries.

Eat less sweets – lollies, chocolate, cakes, biscuits and ice cream. Cut out sugary drinks – soft drinks, cordial, energy drinks, and fruit drinks.

More information:

O Diet fact sheet







Mandy's story

I had my first cigarette at age 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. 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. I walked back inside and life changed forever.

I was closing up the shop and I was counting money and 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'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 having a massive stroke.

It was after my stroke I worked out that 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, 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.

Move more

Not moving enough increases your risk of:

- > Type 2 diabetes.
- > Being an unhealthy weight.
- > High blood pressure.
- > High cholesterol.

Move as much as you can throughout your day. Reduce the time you spend sitting or not moving. Break it up as much as you can.

It's common to have changes to how you move after stroke. Your team can suggest ways to move more that will work for you.

Do jobs around the house. Walk places instead of driving.

Get into activities you enjoy. Go for a walk, kick a ball around, go fishing or work in the garden. Make it social. Invite family and friends to join you, or join a local exercise group.

Be active like this for at least 30 minutes every day. It can be split up into smaller bursts throughout the day. It's okay to start small and build up gradually.

More information:

O Mobility and exercise fact sheet

Rebound after stroke

Eating well and moving more will reduce your risk of stroke.

Get started with the i-REBOUND website. Developed with survivors of stroke, it has:

- > Easy meal ideas.
- > Step by step recipes.
- > Tips for one handed cooking.
- Meal plans and checklists to help you stay on track.
- > Exercise for different levels of ability.
- Exercise videos featuring survivors of stroke.
- > Survivor stories about getting active after stroke.

Visit irebound.enableme.org.au



To check out i-REBOUND, point your phone or tablet camera on this code. Click on the web address that appears.

Notes:	

Maintain a healthy weight

Being over the healthy weight range can cause high blood pressure, high cholesterol and diabetes.

Talk with your team about what a healthy weight is for you.

Start by setting a small goal. Make small changes that will help you get there. Plan to eat well and move more. Once you get there, set another goal.

Getting to a healthy weight is not always easy. Don't give yourself a hard time, the main thing is to keep going. Feel proud of yourself for losing a bit of weight and keeping it off.

Don't smoke

Smoking can damage your arteries and cause a stroke. Breathing other people's smoke also increases your risk of stroke.

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

Talk with your team about what can help you stop smoking.

Nicotine replacement therapy or a stop-smoking medicine can help you quit successfully.

Contacting **Quitline** also 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.

Quitline 13 78 48 quit.org.au

Avoid alcohol

Alcohol can cause high blood pressure and atrial fibrillation.

Alcohol can make diabetes harder to control. It can make it hard to maintain a healthy weight.

The Australian Guidelines say healthy men and women should have no more than 10 standard drinks a week, and no more than 4 standard drinks on any one day.

The Guidelines are for healthy people. Talk with your doctor about what's best for you.

The less you drink, the lower your risk of harm from alcohol. Change your drinking:

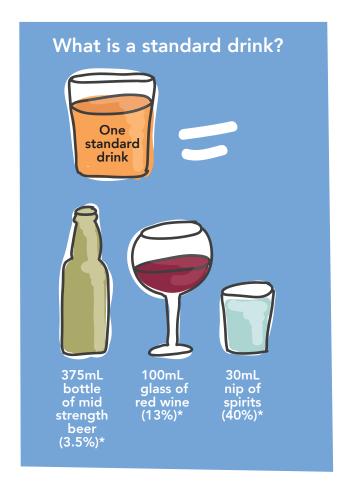
- Check the label to keep count of how many standard drinks you are having.
- > Drink slowly and make every second drink a non-alcoholic drink.
- Drink low or no alcohol beer, wine or spirits.
- Say 'I'm not drinking' or 'I've had one thanks.' You don't need to explain why you're not drinking.

For tips on drinking less, visit hellosundaymorning.org

Counselling Online is a free and confidential service. **counsellingonline.org.au**

My stroke risk factors

Ask your team to complete the My Stroke Risk Factors tool with you. It's on page 10.



Medicine after stroke

After a stroke, most people need to take medicine for the rest of their life.

Blood pressure medicine. Medicines that lower your blood pressure are called anti-hypertensives. Almost everyone who has had a stroke should take anti-hypertensives, even if their blood pressure is normal.

Cholesterol-lowering medicine.

Medicines that lower cholesterol are called statins. Statins are effective in reducing the risk of ischaemic stroke regardless of cholesterol level. Higher dose statins are the most effective, so statins are usually prescribed at high doses, even for people with normal cholesterol levels.

Blood-thinning medicine. If you have had an ischaemic stroke, you will almost always need to take blood-thinners. These medicines reduce the risk of clots forming.

If you have atrial fibrillation or certain heart conditions such as a prosthetic heart valve, you should take anticoagulant medicine.

Take your blood-thinning medicine regularly and be careful not to miss a dose. Your stroke risk goes up very quickly if you miss doses.

Ask your team:

- > What medicine you need to take.
- The amount you need to take.
- > How often you need to take it.
- What follow up you need after you leave hospital.

Never stop taking your medicine or change your dose without talking with your doctor.

Get ready to leave hospital

Discharge planning

Your team will talk with you about leaving hospital.

A good discharge plan relies on good communication between you, your family, and your team. It makes sure you get the right healthcare and services after leaving hospital. It also helps make sure you stay safe and well.

Start thinking about the things you need to do when you are at home. You and your family need to know the easiest and safest ways to do things.

Equipment and changes to your home can help. Your occupational therapist (OT) may visit you at home. They can see what you need and talk with you about it.

You may need more rehabilitation after you go home. You'll probably need follow-up tests and appointments. You may need services to help you.

Make sure you have your medicines to take home with you.

My leaving hospital checklist page 12.

Fill this in when you are getting ready to leave hospital. Ask your team about anything you're not sure about. A discharge summary is a document that explains:

- > Why you were in hospital.
- > What tests and treatment you had.
- > What medicine you are taking.
- What appointments and services have been organised for you.

You should get a copy of your discharge summary when you leave hospital or just after you get home. You also need a list of your medicines.



Your general practitioner (GP)

Your GP will:

- > Make sure you have your medicines.
- Check your blood pressure and cholesterol.
- Look after any health problems you have.
- Refer you to any specialists or allied health professionals you need to see.

Your GP should get a copy of your discharge summary.

Make an appointment to see your GP within a week of leaving hospital.

Take your list of medicines with you when you go to see your GP. Take this book too.

Get ready to care for someone: information for family and carers

As the time comes to leave hospital, you may find yourself taking on being a carer.

Anyone can be a carer. Carers look after a family member or friend who needs help with their day-to-day living.

It's important to talk to your team about what life will be like at home.

Make sure they understand your other responsibilities. Be clear about anything you don't feel comfortable doing. Services may be available to help.

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

Make sure you feel confident about the plan before your family member goes home. Ask who can help if you have a question or something goes wrong. Get their details.

My leaving hospital checklist page 12.

Fill this in when you are getting ready to leave hospital. Ask your team about anything you're not sure about.

Carer services

If you look after someone, you need to look after yourself too.

Carer Gateway is a free support service especially for carers. Carer Gateway aims to make your life easier. Carer Gateway can help you to find local services and support.

Carer Gateway 1800 422 737 carergateway.gov.au

Carer payments

Carer payments are for people who provide care at home for someone with a severe disability or medical condition, or who is frail and aged.

Eligibility depends on your circumstances, and there is an income and assets test.

Centrelink 132 717 humanservices.gov.au

Depression and anxiety

Family members and carers can experience depression and anxiety. Read page 32 to find out more.

Be aware of the signs of depression and anxiety. You can get support and treatment. There are things you can do that will help.



Tracey's story

Mark's stroke was a big one.

I suggested to Mark he stay in bed a bit longer that morning. When I went to check on him, he had fallen out of bed and was unconscious on the floor. Everything is a bit of a blur from that moment. Mark's mum called triple zero (000) and the ambulance crew arrived before I knew it.

Mark had a haemorrhagic stroke and needed surgery to relieve the pressure in his head. When the surgery was over, Mark's prognosis was not good. He was in intensive care for two weeks, the stroke unit for five weeks and a rehab centre for five months.

Mark was in a wheelchair, paralysed on his right side. Communication was challenging due to aphasia. Mark had to relearn to swallow and sit up among many other things.

I was determined to see if we could make life work at home. It wasn't easy at first. The transition from hospital to home was overwhelming. It was physically and mentally exhausting.

You find yourself juggling the usual day-today tasks, while trying to work out what services are available and how to access them. All while dealing with a form of grief. We had therapists coming in and out, so there were times when home didn't feel like our special place anymore.

But I had to trust my instinct that living in the family home was the best decision. I am so glad I did. Mark is the love of my life and while becoming his carer was a huge adjustment, there were many rays of sunshine.

I have a strong network of family and friends, but it was not in my nature to ask for help or accept it when it's offered. I've learnt I am better for everyone when I make time for myself.

I connected with a group of women who also live with their husbands, who are survivors of stroke. While we are all different, our experiences are similar and our bonds are deep. We understand each other. There is no judgement. We can cry on each other's shoulders, and we can lift each other up. I am lucky to have them in my life.

I choose to be Mark's carer. He is as beautiful and kind as he was before his stroke. The love is the same, even though our lives are different.

Get help at home

StrokeLine



Going home after a stroke can be a bit of a shock. Things may be different to what you expected. You can notice problems more when you're at home. New problems can emerge.

The StrokeLine team includes nurses, occupational therapists, physiotherapists, speech pathologists and social workers. Between them they have decades of stroke care experience. They know the system inside out.

StrokeLine can give you information, advice and support. They will:

- > Answer your questions.
- > Tell you about things that will help.
- > Connect you to services.

StrokeLine is a free, confidential and practical service.

StrokeLine is open Monday to Friday, 9am to 5pm Australian Eastern Time.

StrokeLine is closed on Australian national public holidays.

Call **1800 787 653**. Email **strokeline@ strokefoundation.org.au**

Use an interpreter

- 1. Call the Telephone Interpreting Service 13 14 50.
- 2. Say the language you need and wait for an interpreter.
- 3. Ask the interpreter to call StrokeLine 1800 787 653.

Connect with other survivors, family members and carers

You're not alone after stroke. There's a community of people ready to connect with you.

Share stories, information and support with people who are on the same journey.

There are many ways to connect. Find what works for you.

Watch videos, listen to podcasts and read blogs

Discover stories and get practical advice day or night.

Visit enableme.org.au and young.strokefoundation.org.au

Connect online

Contribute to forums, have a chat, join a video meeting or join a social media group.

Be a part of Australia's biggest online stroke community.

enableme.org.au

genyus network is a place to connect with other young survivors. genyus has private forums, topic discussion threads and social meetups.

genyusnetwork.com

Social media groups are an easy way to connect with others. StrokeLine has a list of social media groups. They can help you find the right one for you.

Call **1800 787 653**. Email **strokeline@ strokefoundation.org.au**

Meet face to face

There are stroke support groups across Australia.

Visit **enableme.org.au** to find a group.

StrokeLine can help you find a local group.

Call **1800 787 653**. Email **strokeline@ strokefoundation.org.au**

Stroke Associations

If you live in Victoria, New South Wales or South Australia, your stroke association can help you find a support group.

Stroke Association of Victoria

03 9670 1117 strokeassociation.com.au

Stroke Association of New South Wales

1300 650 594 strokensw.org.au

Hospital Research Foundation Group – South Australia

08 8352 4644 stroke.org.au

Aphasia groups and choirs

Get information, advice and support from other people living with aphasia and their families. Make new connections and enjoy communicating in a supportive environment.

aphasia.community

You can also call the Australian Aphasia Association **1800 274 274** or visit **aphasia.org.au**

Problems to look out for

Depression and anxiety are common after stroke. Be aware of the signs of depression and anxiety. Read page 32.

Worrying about having another stroke.

It's common to worry about this. If some time has passed and it's still bothering you, talk with your GP. There are things that can help.

Muscle spasticity. If you notice any changes with your muscles, talk with your GP. Stiff and tight muscles can cause long-term problems if you don't get treatment.

Vision. If how well you can see has changed since your stroke, Vision Australia can help.

Vision Australia 1300 84 74 66 visionaustralia.org

Going to the toilet. If you're having trouble controlling your bladder or bowel, Continence Australia can help.

Continence Australia 1800 33 00 66 continence.org.au

Sleep. If you're having trouble sleeping, try to:

- Get up at the same time every day. Get out in the morning sunshine.
- Make sure your bed and bedroom are comfortable, dark and quiet.
- Cut down on coffee and tea, especially later in the day.
- Spend time winding down before going to bed. Try relaxation exercises.

Talk with your GP about sleep.

StrokeLine can give you information, advice and support on any problem that comes up.

Call **1800 787 653**. Email **strokeline@ strokefoundation.org.au**

Get more rehabilitation

Your hospital team will talk with you about rehabilitation for after you go home. After this ends, you may want to keep going with your rehab by seeing an allied health professional.

There are different ways to go about it:

- Medicare-subsidised sessions. Ask your GP about getting a Chronic Disease Management Plan. There's usually a gap payment, so ask when you make an appointment.
- **> Private health insurance**. If you have insurance, ask what you're entitled to. Ask about the gap payment.
- > Community-based rehabilitation.
 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.
 Talk with your GP about this.
- **Your NDIS plan**. Ask the NDIS about help to get better at everyday things and reach your goals.

StrokeLine can help find the best way for you.

Call **1800 787 653**. Email **strokeline@ strokefoundation.org.au**

Disability and aged care services

Disability Gateway. Help for people with disability, their family, friends and carers. If you have a disability, contact Disability Gateway.

1800 643 787 disabilitygateway.org.au

My Aged Care. Help around the house or care in aged care homes. If you are over 65 years of age, contact My Aged Care.

1800 200 422 myagedcare.gov.au

Aids and equipment

National Equipment Database. Help with advice on equipment to make things easier at home.

1300 885 886 askned.com.au

AT Chat. Discover assistive technology so you can get on with living your life.

atchat.com.au

Fact sheets

Our fact sheets have more information on managing your health and living a good life after stroke.

Alcohol	Fatigue	Pain	Shoulder, arm and hand
Communication	Incontinence	Palliative care	Supporting children after a family member's stroke
Depression and anxiety	Medication	Personality and behaviour	Swallowing
Diet	Movement and exercise	Return to work	Thinking and perception
Driving	Muscle spasticity	Sex and intimacy	Vision

To get our fact sheets:

- > Ask your hospital team
- Call StrokeLine 1800 787 653 Email strokeline@strokefoundation.org.au



To see our fact sheets, point your phone or tablet camera on this code. Click on the web address that appears.

Money

Centrelink may give you payments if:

- You have an illness, injury, disability or carer responsibilities.
- 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.

Centrelink 132 717 humanservices.gov.au

If you're having trouble with Centrelink, call your state's welfare rights organisation. StrokeLine can give you the details.

Call **1800 787 653**. Email **strokeline@ strokefoundation.org.au**

Ask your **superannuation fund** if you have insurance as part of your super. If needed, ask if you can get access to your superannuation.

The **National Debt Helpline** gives advice on money problems. They can refer you to a financial counsellor. They can help you sort things out.

National Debt Helpline 1800 007 007 ndh.org.au

Post-traumatic growth

Post-traumatic growth is the positive change that emerges after a crisis. It's part of our natural capacity to learn and grow from difficult experiences.

Post-traumatic growth sees us:

- Appreciating and being grateful for life.
- Acknowledging our own personal strength.
- **>** Being more connected with others.

- > Seeing new possibilities in life.
- > Experiencing spiritual growth.

Being able to process the feelings you have about your stroke and recovery is key. Part of this is the thinking and feeling we do ourselves. Part of it is the talking and sharing that we do with others – with family, friends and health professionals.

Neuropsychologist Jamie Berry advises, "Process the experience deeply, look to the future, and look for a meaningful life. Think of the most meaningful life you could have, and work towards that."

For many survivors and families, making meaning and making a difference is a part of their recovery.

If you haven't noticed signs of this in your recovery, that's okay. Just keep an eye out.



When I was introduced to the idea of post-traumatic growth, I was seven years post stroke. I could reflect back on my experiences and see it. There is no doubt stroke is a traumatic event.

What post-traumatic growth

says is that life can be better, it doesn't have to be worse. To be introduced to the concept was very empowering.

Adrian, survivor of stroke

To find out more, visit young.strokefoundation.org.au

Get help 24 hours a day, 7 days a week

Service	Contact if	Details
Ambulance	Someone has signs of stroke	Call triple zero – 000
Healthdirect	You need to speak with a nurse about any health issue	1800 022 222 healthdirect.gov.au
Lifeline	You are feeling overwhelmed, need crisis support or need to talk something through	13 11 14 lifeline.org.au
Beyond Blue	You need help with anxiety and depression	1300 22 46 36 beyondblue.org.au
13YARN	You want to talk with an Aboriginal and Torres Strait Islander Crisis Supporter	13 92 76 13YARN.org.au
1800 Respect	You need support for domestic, family or sexual violence.	1800 737 732 1800respect.org.au

Learn the F.A.S.T. signs of STROKE RACE ARMS Can't be raised? SPEECH Surred or confused? If you see any of these signs Act FAST call 000 (triple zero)





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 evident. I realised the importance of focusing on my emotional obstacles in my 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 be true to my value of health and wellbeing 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 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 Gee is the author of 'Reinventing Emma'.

Strokesaurus

Here are the most common medical words. For more, visit **enableme.org.au**

Aphagia

Unable to swallow.

Aphasia

Difficulty talking, reading, writing or understanding. Also called dysphasia.

Apraxia

Difficulty planning movement.

Arrhythmia

Any condition where the electrical activity of the heart is irregular, faster or slower than normal.

Aspiration

Food, drink or saliva goes into the windpipe and lungs, instead of into the stomach.

Ataxia

Difficulty coordinating movements.

Atrial fibrillation (AF)

Irregular heartbeat. One of the smaller heart chambers doesn't coordinate the pumping of blood properly. Blood can stagnate and clots can form. These clots can then travel to the brain.

Coagulation profile

Tests the time it takes your blood to clot. Also called clotting test.

Cognition

Thinking, memory and judgment.

Contracture

A joint becoming fixed in one position.

Diplopia

Double vision.

Disinhibited

Saying or doing things that are not usual, unexpected or seem strange to others.

Dysarthria

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

Dysphagia

Pain or difficulty swallowing.

Dysphonia

Weakness or paralysis in the muscles in and around the vocal cords.

Electrical stimulation

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

Emotional lability

Emotional responses that don't seem to make sense or are out of proportion. You may cry or laugh for no good reason. You may laugh at something sad.

Fibreoptic endoscopic evaluation of swallowing (FEES)

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

Foot drop

Muscle weakness or contracture cause the foot or ankle to drop down.

Geriatrician

Doctor who specialises in working with older people.

Hemianopia

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.

Homonymous hemianopia

Loss of the same half of the visual field in each eye.

Hypotonia

Muscles are floppy or loose.

Impulsive

Doing things without thinking it through.

Infarct

An area of brain that has been injured.

Insight

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

Judgement

Ability to make good decisions.

Mobility

Moving, walking and standing.

Muscle spasticity

Muscles that feel stiff and tight. They resist movement. They may not work like you want them to.

Nasogastric tube (NG tube or NGT)

A tube is passed through one nostril down the back of your throat and into your stomach. Liquid nutrition and medicines go through the tube.

Neglect

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

Neurologist

Doctor who specialises in conditions of the brain and nervous system.

Neuropathic pain

Changes in your brain make you feel pain, even if you're not injured. Also called central post-stroke pain (CPSP) or nerve pain.

Neuroplasticity

After a stroke, pathways in the brain can change. Uninjured parts of the brain can take over the jobs of injured areas.

Nystagmus

Constant, unsteady movement of the eyes.

Orientation

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

Patent foramen ovale (PFO)

A PFO is a small hole between the two sides of the heart. Babies need this connection before they're born. It usually closes after birth, but can stay open in some people. Clots that form in veins can cross to arteries that supply blood to the brain.

Percutaneous endoscopic gastrostomy (PEG)

A tube is inserted through the skin on your stomach. Liquid nutrition and medicines go through the tube.

Perception

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

Perseveration

Getting stuck on one idea, action or response.

Plaque

The build up of fats, cholesterol and other substances in and on the artery walls.

Proprioception

Ability to sense where parts of the body are and how they are moving in space.

Recognition

Knowing what objects or parts of your body are.

Rehabilitation physician

Doctor who specialises in the rehabilitation of patients.

Quadrantanopia

Loss of either the upper or lower quarter of the visual field.

Spasticity

See muscle spasticity.

Shoulder subluxation

The upper arm bone sits slightly lower in the shoulder socket.

Strabismus

Crossed eyes.

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.

Videofluoroscopy

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

Visual field

Your visual field is the entire area you can see when your eye is directed forward.

Visual inattention

When a person ignores everything on one side. Even when they're reminded of that side, they quickly forget it exists.



How to get more involved

- **6** Give time become a volunteer.
- Raise funds donate or hold a fundraising event.
- Speak up join our advocacy team.
- Y Leave a lasting legacy include a gift in your Will.
- **H** 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
- f /strokefoundation
- @strokefdn
- © @strokefdn