

Keep this with you from hospital to home

About Stroke Foundation

Stroke Foundation is a national charity that partners with the community to prevent, treat and beat stroke. We stand alongside survivors of stroke 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 for more information.

Warning

This book may contain images, stories and names of Aboriginal and Torres Strait Islander people who have passed.

Acknowledgement

Thank you to everyone who contributed to developing Our Stroke Journey. Our particular thanks go to the people who share their story in this book. Thanks also to the Queensland Aboriginal and Islander Health Council, who led the initial consultations and the design of Our Stroke Journey. We also thank the Elizabeth and Barry Davies Charitable Foundation and Federal Parliament Press Gallery Midwinter Ball for their generous support.

Stroke Foundation acknowledges the ancestors and Traditional Custodians of the land on which our offices stand and pay respect to Elders past, present and emerging.

© No part of this publication can be reproduced by any process without permission from Stroke Foundation. July 2021.

Suggested citation: Stroke Foundation, Our Stroke Journey, Melbourne, Australia.

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

About this book

Most people don't know much about stroke. This book answers the questions:

- What is a stroke?
- How will my stroke change me?
- How do I look after my health?
- How do I get ready to go home?
- How do I sort things out once I'm at home?

The stories from survivors of stroke, families and health workers give you an idea of the road ahead. You don't need to read the whole book. Use the list on page 1–2 to find the information you need.

Keep this book with you – it belongs to you.

Using this book

You and your family can write notes in this book. There are parts you and your hospital team can fill in together.
Once you go home, show this book to anyone helping you look after your health.

For family and friends

If family and friends would like a copy of this book, ask your hospital team or call StrokeLine on 1800 787 653.



StrokeLine

Talk with StrokeLine's health professionals about getting better and being healthier after your stroke.

Anyone can call StrokeLine. It's free and we take time to listen. We'll tell you about different things that can help after a stroke. We can help you find the support and services you need.

It's free to call StrokeLine.
Call StrokeLine on 1800 787 653.
We're here Monday to Friday 9am
to 5pm, Eastern Standard Time. You
can leave us a message outside these
times and we'll call you back. Email
strokeline@strokefoundation.org.au

Contents

What is a stroke?3
My stroke5
Signs of stroke 6
Tests 8
Treatment9
Your hospital team10
For family and carers 14

Rehabilitation32
Working on your rehab 33
Getting back to work 34
My stroke rehab plan 35
Help to get better 37
Annette and Sheena's story38
For family and friends 40

How will my stroke change me?15
Will I get better after my stroke?16
Justin's story18
Arms, legs and muscles 20
Using words21
Swallowing22
Thinking and personality 23
How you see24
Touch, taste and smell 25
Pain25
Going to the toilet25
Feelings 26
Sex and relationships 27
Feeling tired28
Want to know more? 29
Harry's story30

How do I look after
my health?41
High blood pressure 43
High cholesterol43
Diabetes44
Atrial fibrillation44
Other medical problems 45
Medicine after stroke 46
Smoking47
Alcohol47
Joe's story48
Eat healthy foods50
Be a healthy weight 53
Be active 53
My stroke risk factors 54

Contents

How do I get ready to go home?55
Planning to leave hospital56
Angela's story58
For family and carers 60
My leaving hospital checklist61
My appointments and services

How do I sort things out once I get home?63
Looking after your health64
Aboriginal Community Controlled Health
Organisations
Getting more rehab 66 Driving 67
Rebecca's Story68
Changes after stroke 70
Support after stroke 71
For families and carers 72

What is a stroke?

What is a stroke?

A stroke is when blood can't get to all parts of your brain.

Blood flows through your arteries. Arteries are like tubes or pipes. If blood can't get through, your brain can be hurt.

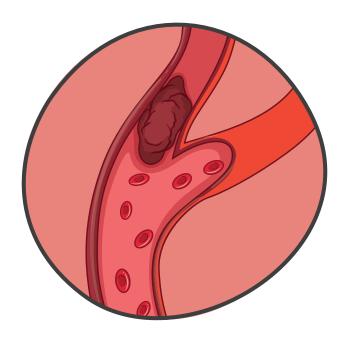


There are two types of stroke:

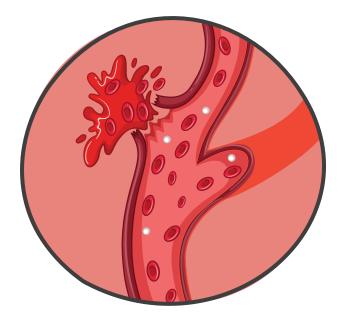
- Your arteries can get blocked. This stops the blood getting through. This is called an ischaemic stroke. It's said like this: is-key-mick.
- Your arteries can break.
 Instead of going through
 the artery, blood leaks into
 the brain. This is called a
 haemorrhagic stroke. It's said
 like this: hem-or-ragic.

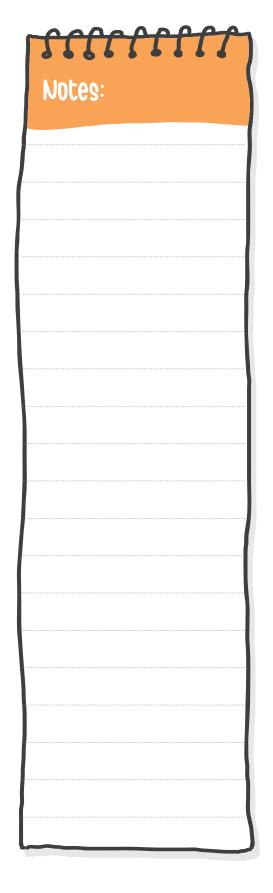
My stroke

Ischaemic stroke



Haemorrhagic stroke





Learn the signs of STROKE



FACE

drooped?



ARMS

can't be raised?



SPEECH

slurred or confused?



TIME

is critical! Call 000.

If you see any of these signs

Act FAST call triple zero (000)



Signs of stroke

Never ignore the signs of stroke. Always call triple zero (000) if you have any of the signs. The F.A.S.T. test is an easy way to remember the signs of stroke. There can be other signs too, such as:



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

Tests

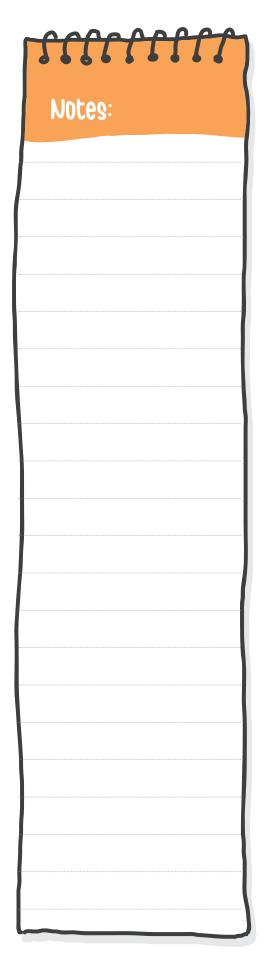
At the hospital, you'll have tests to find out:

- What type of stroke you had and what caused it.
- What part of your brain is hurt and how badly.

After a stroke everyone should have a brain scan. Brain scans take pictures of your brain. These are called a CT or MRI scan.



Your nurse 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.

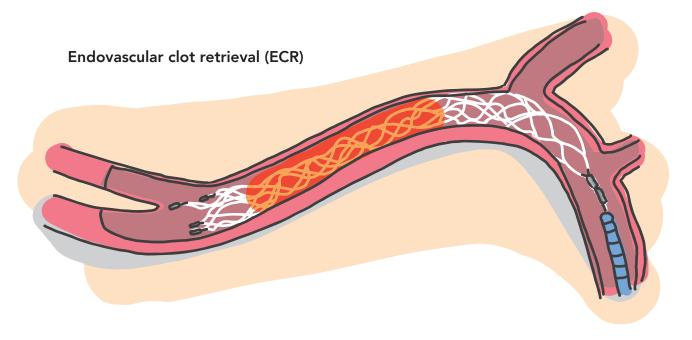


Treatment

Ischaemic stroke

Doctors and nurses may give you medicine to unblock your artery so the blood can get through. The medicine is given through an injection in your arm. This is called **thrombolysis**. It's said like this: **throm-bol-eye-sis**.

You may also have an operation to unblock the artery. Your doctor puts a tube into an artery in your leg and feeds the tube up into your brain. A small device in the tube grabs the blood clot and pulls it out. This is called **thrombectomy** or **endovascular clot retrieval** (ECR). It's said like this: **throm-bek-tom-ee**.



Haemorrhagic stroke

Doctors and nurses may give you medicine to slow down or stop the bleeding in your brain.

You may need an operation to:

- Remove blood from your brain.
- Fix an artery in your brain.
- Relieve pressure in your brain.

The doctors and nurses will talk with you and your family about whether these treatments are right for you.

Your hospital team

Everyone should have a hospital stay after a stroke. Your hospital team will talk to you about your health. They'll help you get better.



Aboriginal Liaison Officers help you and your family while you're in hospital.



Doctors look after your medical care. They organise tests and treatment.



Nurses look after your treatment and care.



Speech pathologists help with swallowing, talking, reading and writing.



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



Physiotherapists help you sit, stand, move and walk.



Occupational therapists help you get back to doing things that are important and meaningful to you.



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



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



Pharmacists talk with you about medicines, and make sure you have the medicines you need.

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.

Working with your hospital team

Write things down

Use this book to:

- Write down people's names.
- Keep a list of questions you want to ask.
- Take notes when people tell you things.

If you can't write easily, ask your team, family or friends to do it.

Ask questions and talk about any worries

Talk to your team:

- When you don't understand.
- When you're worried.
- If you need more time to make a decision.

Ask lots of questions. Your team will be happy to answer them.

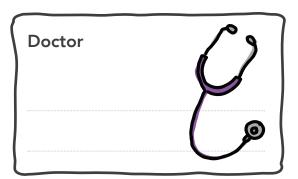


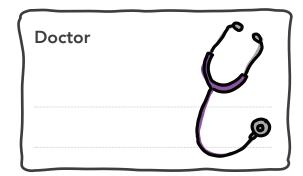
My hospital team

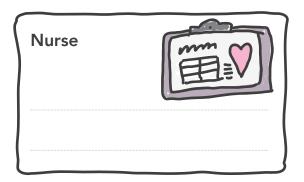


Write down your team member's names:



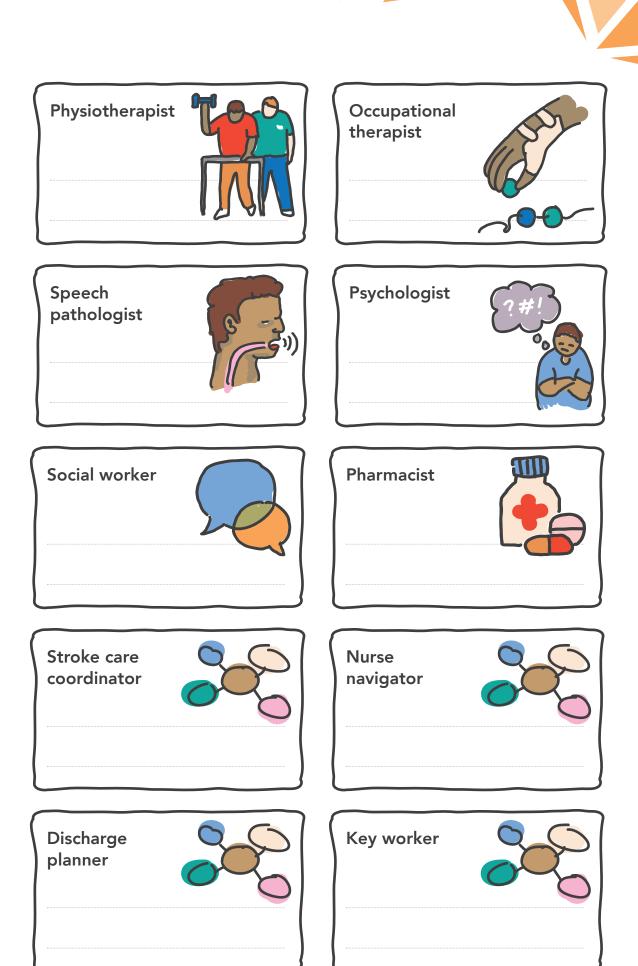












For family and carers

Having someone in hospital

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

- Spend a lot of time at the hospital.
- Talk with the hospital team about your family member. If they're really sick, you may need to make decisions for them until they're better.
- Be on the phone letting family and friends know what's going on.
- Keep everything going at home.

Make sure you take time to rest. Ask family to visit at the hospital so you can take a break. Talk to the Aboriginal Liaison Officer if you need support with this.

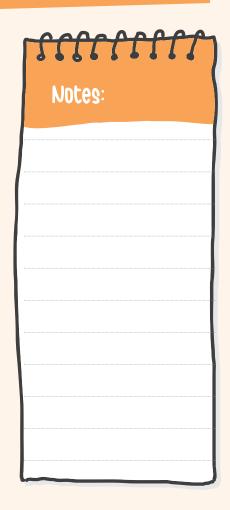
If people offer to help, accept it.

Family and friends can help with:

- Visiting your family member.
- Driving you places.
- Looking after kids and family members.
- Doing the shopping and cooking.
- Cleaning and helping with the garden.

Being in hospital and away from home can be hard. Talk to your hospital team if your family member wants to leave hospital and head home.

The Aboriginal Liaison Officer and the hospital social worker can help with being in hospital, keeping things going at home and making it safe for the family member to go home.



How will my stroke change me?

Will I get better after my stroke?

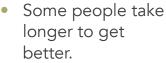
Our brain controls everything we think, feel, say and do.

Different parts of the brain control different things. How your stroke changes you depends on:

- Which part of your brain was hurt.
- How badly it was hurt.

Everyone's stroke is different.

Most people get a lot better.



 Some people may not get better.

> Your hospital team can help you get better.

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

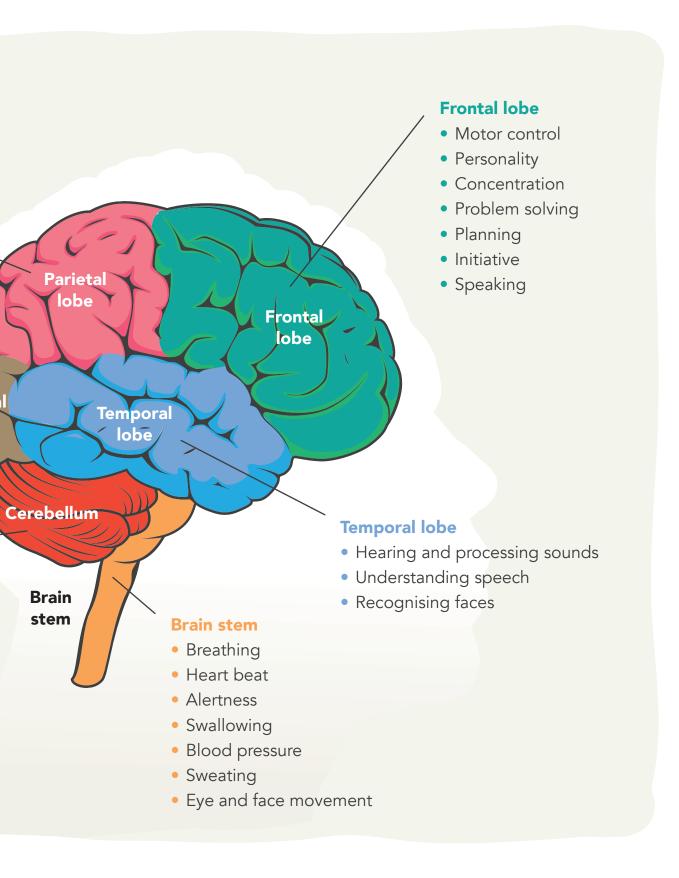
Cerebellum

- Balance
- Control of movement

Occipita lobe

- Posture
- Fine motor skills





Justin's Story

I had a stroke in 2014 when I was 32 years old. I was at home with my wife when it happened. She noticed that I was walking funny, and she took me to hospital. I was in hospital for around one month and needed rehab to learn to walk again.

I struggled not smoking while in hospital, the nicotine withdrawal was very difficult. I was a very disruptive and angry patient because I didn't have any nicotine patches. Once they worked out that I needed a patch, I was fine.

When I was in hospital, I was desperate to go home again. Once I got home, it was very different. I found a lot of things strange and wanted to go back to hospital because I felt more comfortable there.

I went back to hospital for outpatient rehab for speech therapy, occupational therapy and physiotherapy. I am grateful that I am now able to walk again, but I have lost the use of my right arm which makes life a bit challenging at times.

The stroke also affected my family. I have four children, but I lost some of the bond with them when I was unwell. I missed out

on taking them to school, seeing them play sport and all those things. There was definitely a lot of strain on my wife and family. I am trying to make up for lost time with my grandchildren now.

I have made many changes to my lifestyle since my stroke. I've quit smoking and drinking alcohol. I used to love sugar, I don't have sugar in my tea or coffee now. I eat a lot of fresh food and vegetables and only buy good quality meat. I don't want to preach to people about how they live their lives, but I would recommend doing things in moderation, stay active, eat good food and quit the smokes.

These days I really enjoy getting out for a drive. I've had my car modified so I can drive without using my right arm. Driving gives me my freedom. I can do whatever I want when I'm out and I like being in the car by myself. It makes me happy.

If I met a young person who had a stroke, my advice would be to take your time. There's no rush with recovery, there is no race. Because that's one thing that I did, I rushed a lot of things to try and get back to how things used to be. Try and relax because when a stroke happens, life changes, everything slows down. Take your time.



Arms, legs and muscles

Your arms, legs and hands may not work like they used to.

This can change how you sit, stand, balance, walk and move. Your muscles may be weak and floppy. Your brain may have trouble getting them to move.

Your physiotherapist and occupational therapist will:

 Check how you're moving, to make sure you're safe.

 Help you with treatment and exercises so you can get better.

 Make sure you have things like a stick or walking frame if you need them.

Your muscles may feel stiff and tight. This is called **muscle spasticity**. Your physiotherapist and occupational therapist can give you treatment and exercises that will help.

Keep using your arms and legs to help them get better. Move as much as is safe for you to do.



Using words

You may find:

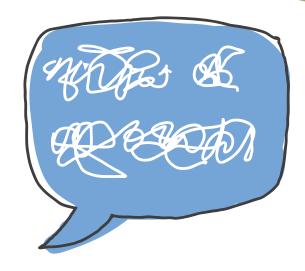
- It's hard to think of the right word.
- You use the wrong word or sound.
- You don't understand what someone is saying.
- You have trouble reading and writing.

This is called **aphasia**. It is said like this: **ay-fayz-ee-uh**.

Try a mime, writing a word or drawing something to help get your message across if the words don't come.

Ask your family and friends to:

- Yarn with you somewhere quiet.
- Face you when talking with you.
- Make sure there's only one person talking at a time.
- Talk slowly and keep it short.
- Check you understand.



If the muscles you use to talk don't work properly, your speech will be slurred. This is called **dysarthria**. It is said like this: **diss-arth-ree-uh**.

Your speech pathologist can help you exercise and practise. They can give you things like books, cards and a board to help you communicate.

These problems can make life hard. You may feel like you aren't a part of things. If you're feeling sad, down or worried, let your hospital team, family and friends know.

People can help by:	

Swallowing

You can have trouble swallowing food and drink.

Food or drink can go down the wrong way. It gets into your lungs instead of your belly. This can make you really sick.

Your speech pathologist can find out what the problem is. They may give you exercises to improve your swallowing.

You may need:

- Someone to help you when you eat and drink.
- To have thick drinks or soft food.
- To eat and drink slowly, taking small mouthfuls and sips.
- To sit up straight while you eat and drink, and for a while afterwards. Your speech pathologist will show you the right sitting position, as well as the right position for your head.



Thinking and personality

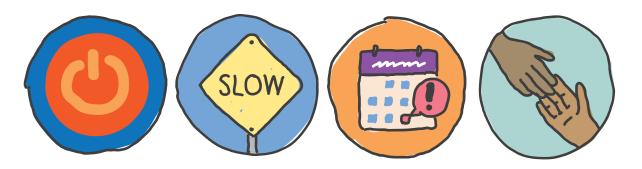
Your thinking can change.

It may be hard to:

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

It helps to:

- Turn off the TV or radio.
- Slow down. You don't need to finish a big job in one go.
- Use your phone, calendar or pictures to help you remember.
- Talk to people about what's changed since your stroke. Tell them when you're having trouble. Let them help.



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.

Your hospital team can talk with you about what has changed and what can help.

How you see

How well you see can change.



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



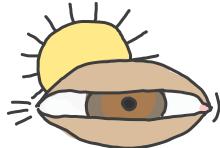
You may see double.



Things may be blurry.



Your eyes may move all the time.



They may be more sensitive to light.

It may get better in the first few months. It may not get back to how it was before. Your hospital team can show you how to make things easier and safer.

Touch, taste and smell

Stroke can change how:

- You feel touch, hot and cold.
- Things taste or smell.

You may not know where parts of your body are. You may ignore people and things on one side of your body. You may have no feeling, or pins and needles.

When you are in a busy, noisy place, you can feel like it's too much.

Your hospital team can talk with you about how to make things easier and safer.

Pain

You may feel pain because:

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

Your hospital team can help with exercises, positions and special equipment.
You may need medicine.
Be active—
move as much as you can.

Going to the toilet

You may have trouble:

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

Your hospital team can find out what the problem is and what will help.

Feelings

You may laugh or cry for no good reason. You can tell people "Don't worry, it's just part of my stroke". If it's bothering you, go somewhere quiet or do something else for a while.

After your stroke, you may worry about whether you will get better. You may feel sad about the change from how you were before.

Worrying about another stroke

It's normal to worry about having another stroke. If some time has passed and it's still really bothering you, talk with your hospital team.

Talk with your hospital team, family and friends about how you are feeling.

Depression and anxiety

If you feel sad or down for more than two weeks, you may have depression. You may:

- Lose interest in things.
- Not have much energy.
- Have trouble sleeping or sleep more than usual.

Anxiety is when you feel worried or nervous all the time or for no real reason.

Never ignore depression or anxiety. You can get treatment and most people do get better.

Eat healthy food and move as much as you can. Get into activities you enjoy. Spend time with people who make you feel good.



Sex and relationships

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

Having sex doesn't cause strokes. For lots of people, getting back to having sex is part of getting better.

You may have trouble with:

- How well you can move.
- Muscle weakness, stiffness or tightness.
- How you feel touch, as well as pain.
- How you go to the toilet.
- Feeling tired.

All these things can change how you feel about sex.

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

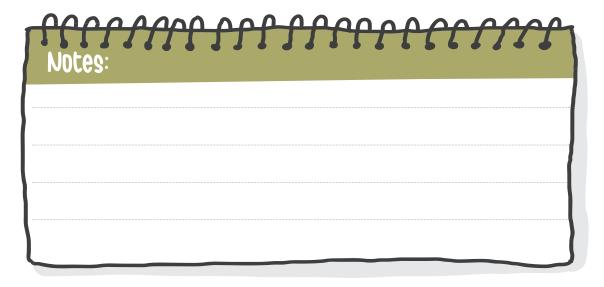
If you're feeling sad, down or worried, you may not feel like having sex. You may not be as confident as you were before.

Your relationship can change:

- Your partner may be helping you more with things.
- You may worry about whether your partner still finds you attractive.
- Your partner may worry about annoying you, making you sad or hurting you.

Talk with your partner when you're ready.

It can be hard to talk to your hospital team but it's okay. They're used to talking about sex and relationships. You may need to know how to do things differently. They know ways to make sex easier and more enjoyable.



Feeling tired

Feeling very tired after a stroke is called fatigue. It's very common. It can help to:

Balance activity and rest.

Rest regularly before you feel tired. Do small amounts of physical and mental activity in between rest breaks.

Do things in ways that take less energy.

Your occupational therapist can talk with you about this.

Eat a healthy diet and drink water.

Drinking alcohol may make it worse.







Most people don't know fatigue can be a problem after a stroke. Family, friends and people at work may not understand why you are so tired and can't do things. Talk to people about how you are feeling.

If you're having trouble sleeping, talk with your hospital team.

Notes:	M M	PAPPP.	ereer.	M

Want to know more?

There are fact sheets on how stroke can change you, and what helps.

Your hospital team can give you copies. You can also call StrokeLine on 1800 787 653 to ask for copies.

After stroke fact sheets:

- Aged care homes after stroke
- Alcohol after stroke
- Communication after stroke
- Depression and anxiety after stroke
- Diet after stroke
- Driving after stroke
- Emotional and personality changes after stroke
- Fatigue after stroke
- Incontinence after stroke
- Medication after TIA and stroke
- Mobility and exercise after stroke
- Muscle spasticity after stroke
- Pain after stroke
- Palliative care after stroke
- Return to work after stroke
- Sex and relationships after stroke
- Swallowing problems after stroke
- Supporting children after a family member's stroke
- Thinking and perception after stroke
- Upper limb management after stroke
- Vision loss after stroke





https:// strokefoundation.org. au/factsheets

Harry's Story

I have been working at Alice Springs Hospital as an Aboriginal Liaison Officer (ALO) and interpreter for the past three and a half years.

In my team there are nine ALOs who speak eight different local languages. Our role involves looking after cultural needs, interpreting and discussing patients' care needs. We educate non-Indigenous hospital staff about our culture so they can understand patients better.

Interpreting and breaking down the language barrier is a big part of the job. For most of our people, English is our third, fourth or fifth language, it is like a foreign language. I was lucky to learn English at school and still have my native language.

I am able to teach my team how to communicate with patients from Uluru, the desert region where I am from. I also help break down medical jargon into simple language that patients can relate to.

My job, and my team's job is to help survivors of stroke and their families understand their needs, make them feel comfortable, and support them to get better and return home to Country. If anyone has a problem or something is bothering them, whether it's got to do with nursing, their care or cultural needs, they can always talk to us, the ALOs.

Homesickness and loneliness can be a big problem. Sometimes people, especially the elderly, have never been to hospital before, and some of them have never left their community. We're there to help and show we understand how they feel. It can just be saying, "Look, we come from community as well, but we live in town and work here to help out people like you that come in from remote communities." People get homesick and lonely because they are far from where they belong. Their belonging is back on country.

The shirt that I am wearing, it was designed by a fellow ALO and symbolises patient centered care. It represents a sick person walking in to see the specialists in the hospital, coming in with weak footprints, then going out after seeing the specialist, with healthy, strong footprints. Our work is all about the patient's journey. The most rewarding part of my job is helping patients on their recovery journey.

Harry, Aboriginal Liaison Officer and proud Anangu man



Rehabilitation

Rehabilitation is where you work on things that have changed since your stroke.

Your hospital team will begin working on your rehabilitation when you are well enough.

Rehabilitation is called rehab for short. In rehab, your hospital team will help you to:

Do things again.



You'll have checks and tests to help your hospital team understand:

- What's different since your stroke.
- What will help you get better.

You'll do a lot of exercises. You'll do many of them again and again.

Everything you do is a part of rehab. Having a wash, getting dressed, moving around, making a drink and a meal are all part of it.

There are special rehab services. You may have:

- Inpatient rehabilitation at a hospital.
- In-home rehabilitation your rehab 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.

By the time your hospital team talks with you about rehab, you may be in a hurry to get home. If they think you would be better off staying in hospital for rehab, have a good think about it. Ask them lots of questions so you can make the best decision for you.

More rehab will make life easier and safer once you go home.

Working on your rehab

Rehab helps your brain change.

If part of your brain has been hurt, a different part can learn to take over its job.

This helps you get better, but it takes a lot of work to make it happen. To make the most of rehab:

Talk with your team. Tell them:

- What's most important to you.
- What's working well for you.
- What's worrying you.

Get visitors involved. Spend some time catching up, then ask people to help you do your exercises.

Keep doing your exercises again and again. Ask your rehab team about what you can do when you have spare time.

Get enough rest. Rehab is hard work. Take breaks when you need to. Try to get a good night's sleep.

It's normal to feel frustrated or down. Talk with your hospital team, family and friends about it.

Keep going. Sometimes it takes longer than you think it will. Sometimes it feels like you're not getting better.

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



Getting back to work

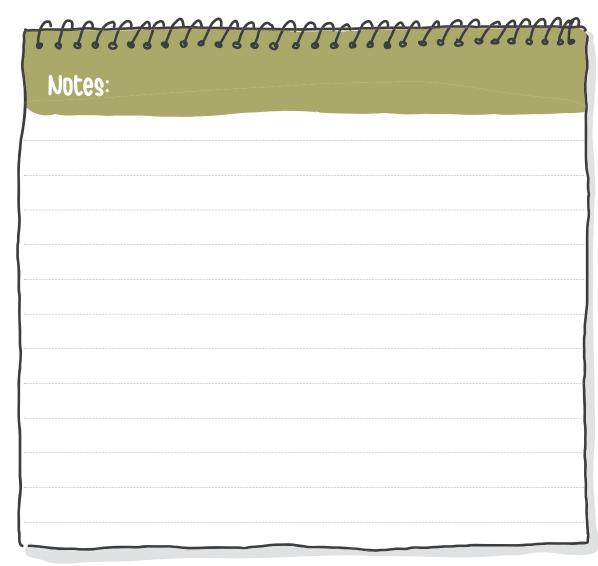
Your rehabilitation team can help you plan to go back to work.

Talk to your team about what to expect and what to do if problems come up. You may need:

- Changes to your job and your hours.
- Equipment or changes to your work to make your job easier.
- More rehabilitation or time before returning to work.

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

Talk with your boss about what you need to return to work successfully. Your hospital team can talk with them about your stroke and what you need.



My stroke rehab plan

Talk with your team. Tell them what's most important to you. Start by asking yourself:

- What do I want to do?
- Where do I want to be in three months or six months?

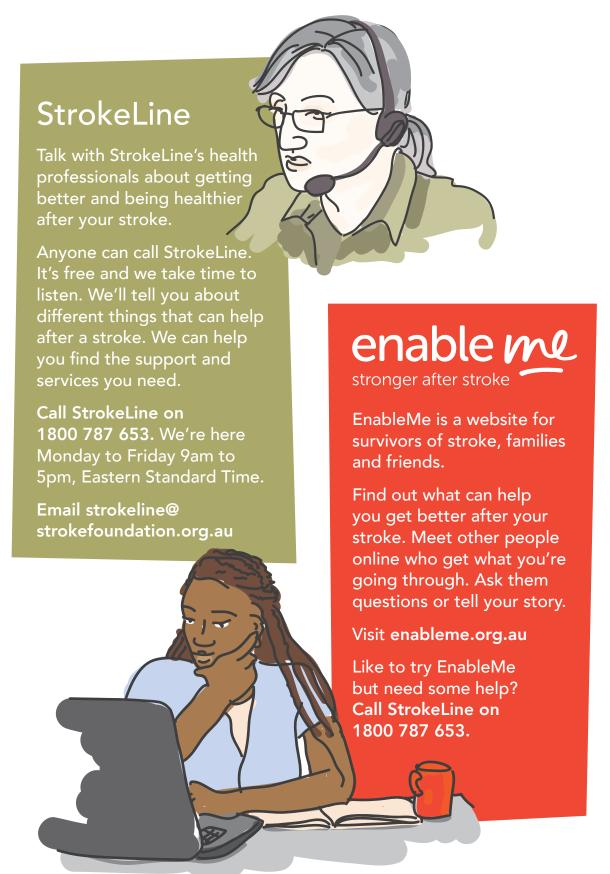
Your hospital team can help you get there. They'll help you:

- Pick some things you can achieve quickly, and some things that will take longer.
- Make a plan, breaking things down into steps.

I WANT TO:	STEPS:
BY:	
I WANT TO:	STEPS:
T WAINT TO.	SIEF J.
BY:	
I WANT TO:	STEPS:
BY:	

I WANT TO:	STEPS:
97.	
BY:	
I WANT TO:	STEPS:
BY:	
VI.	
LWINT TO:	CTEDC.
I WANT TO:	STEPS:
BY:	
BY:	
	STEPS:
BY: I WANT TO:	STEPS:
	STEPS:
	STEPS:
	STEPS:

Help to get better





Annette and Sheena's Story

John was Annette's husband and Sheena's dad.

When John was 40 years old, he had a stroke. John woke up one morning with his hand closed. He thought he had slept on it funny, but John's hand was closed because he had suffered a stroke and it would no longer open.

The stroke affected the right side of John's body which meant he couldn't write, play tennis, he really couldn't do much.

John was totally reliant on us for more than 12 months. We had to comb his hair, cut up his food, do up his shirt buttons, everything.

Muscle spasms left John in a lot of pain. It was a stressful time. Everyday we supported him to stay mentally strong.

We didn't get any information about stroke. We didn't have a regular doctor or rehabilitation appointments. We didn't meet other people who had been impacted by stroke. We didn't even know that the carer's pension existed back then. It was a very hard time, we had no support from anyone, but we did the best we could.

After 12 months John got the use of his right hand back, then his leg came good. After two to three years, he was able to play

lawn bowls again which was a great achievement. We look back and are filled with pride that we worked together as a family, stuck it out, and supported him throughout his recovery.

For people out there reading this, we want you to know that there is hope after stroke. Our family went through some tough times, but John lived another 20 rich and meaningful years after his strokes. Our message is to have high expectations and hope for your recovery and rehabilitation. It is possible to have a long, active life after stroke.

Our advice for other carers would be to speak up. Talk to a professional and get the help you need for your loved one. If their pain is not being managed or their sleep or mood isn't good, tell someone. If their medication isn't helping, tell someone. If you aren't coping, tell someone. Whether it's a doctor, nurse or the Stroke Foundation they can ring you up and check in to ask how you are doing. Support is key.

As a carer it's also important to have your own life too. Read books, go to the pictures, keep active. You need something to get away. A carer has got to have time out.

Annette and Sheena, carers and proud Yorta Yorta women

For family and friends

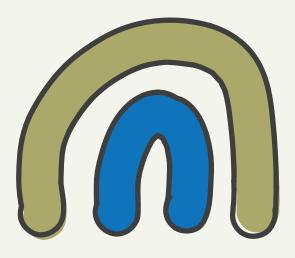
Family meetings

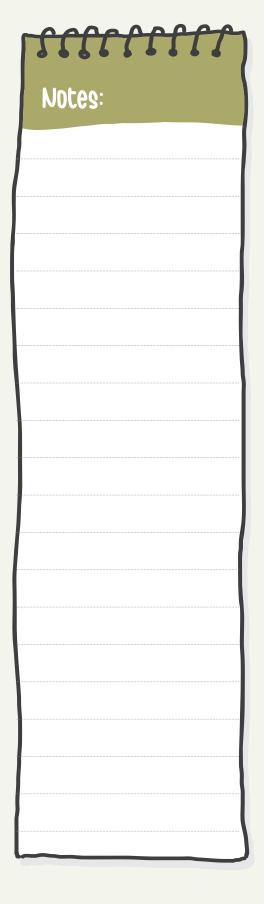
Family meetings get everyone on the same page. They help when it's time to make decisions, especially about going home.

You can ask for a family meeting at any time.

Make the most of a family meeting:

- Make sure everyone in the family knows about the meeting.
- Get people to phone in if they can't get there in person.
- Ask for an interpreter if anyone in the family needs one.
- Write down your questions and the things you want the team to know.
- Make sure someone's taking notes or ask for the meeting to be recorded on a phone.





How do l look after my health?

How do I look after my health?

After a stroke, you need to look after yourself.

A stroke risk factor is something that makes you more likely to have a stroke. Your hospital team will talk to you about your stroke risk factors. They'll let you know what you need to do to keep your risk factors under control. They'll make sure you have any medicines you need.

Doing these things will make a big difference:







- Be active.
- Eat healthy food.
- Be a healthy weight.



Don't smoke.

 If you drink alcohol, follow your doctor's advice on if, when, and how much you can drink.

Most people worry about having another stroke.

The good news is that looking after yourself makes it less likely you'll have another stroke.

High blood pressure

High blood pressure can lead to blocked arteries.

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.
- Get your blood pressure checked regularly.
 Ask your health worker to check it. You can also get it checked at the chemist.
- Be active, be a healthy weight and don't smoke.
- Eat healthy food. Don't have too much salt. Read page 51 to find out more.

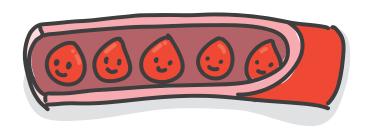


High cholesterol

Cholesterol is a type of fat in your blood. Too much cholesterol can lead to blocked arteries.

Keep your cholesterol under control:

- Take medicine prescribed by your doctor.
- Get your cholesterol checked regularly.
- Be active, eat healthy food, be a healthy weight and don't smoke.
- Reduce the amount of saturated fat you eat. Read page 50 to find out more.





Diabetes

High blood sugar levels can lead to blocked arteries.

Keep your diabetes under control:

- Take medicine prescribed by your doctor.
- Check your blood sugar when you're supposed to.
- Be active, eat healthy food, be a healthy weight and don't smoke.
- If you drink alcohol, your hospital team can tell you if, when, and how much you can drink.

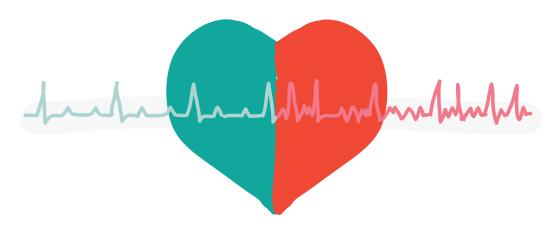


Atrial fibrillation

This is called AF for short. AF is when your heart beats too fast and unsteady. AF can lead to blocked arteries.

Keep your AF under control:

- Take medicine prescribed by your doctor.
- Be active, eat healthy food, be a healthy weight and don't smoke.
- Drink as little alcohol as possible.



Other medical problems

These things can cause strokes:

- Weak or tangled arteries in the brain.
- A hole in the heart.
- Heart problems. If you have had heart trouble in the past, talk with your doctor about it.

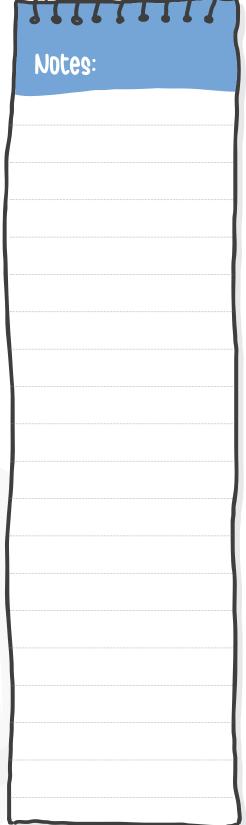
You may need an operation to fix these things.

These things increase women's risk of having a stroke:

Taking the contraceptive pill.

• Taking hormone replacement therapy (HRT).





Medicine after stroke

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

Ask your hospital 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.



Medicine	Dose	How often?	Notes
			4

Smoking

Smoking can damage your arteries and cause a stroke.

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

It can be hard to quit smoking so make sure you ask for help. Talk with your hospital team about what can help you stop smoking.



Aboriginal Quitline is run by Aboriginal people. They'll talk with you about different ways to quit smoking and things that will help.

Call Aboriginal Quitline 13 78 48. Visit quit.org.au

Alcohol

Drinking too much alcohol can increase your risk of having another stroke.

Healthy people should drink no more than 10 standard drinks a week. Don't ever drink more than four standard drinks in a day.

After a stroke, your doctor can tell you:

- **If** and **when** you can drink alcohol.
- How much alcohol you can drink.



*This information is a guide only. For more information go to https://www.health.gov.au

Joe's Story

I had my first stroke when
I was in my early 50's, in a
supermarket of all places.
I was trying to eat a pie, and
I couldn't control my arm and
it ended up all over my face.

I was lucky that I knew the signs of stroke, so I sat down on the floor and told my work-mate 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 last stroke felt like I was on a rocky boat out to sea.

It's so important to know the signs of stroke and to get to hospital immediately. My friend taught me about the signs of stroke and what to look out for. I owe my life to her, as without this knowledge I wouldn't have known what was happening to me. I might not have thought to rush to hospital as quick as I did each time.

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 had some very dark days.

I kept thinking `Was 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?'

I used to wake up at two o'clock in the morning and try not to think about it. This worry also caused lack of sleep and exhaustion, 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 also quit smoking and drinking which really helped me get healthy and back on track. With help from my doctor, 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, keep your stress levels down, drink in moderation.
- 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.



Eat healthy foods





Vegetables.

Fresh, frozen, dried 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. Eat kangaroo, lean beef, goanna, emu, chicken, turkey and goose. Get into fresh fish, prawns, pippis, mussels and oysters. Tinned tuna, salmon and sardines are good.

Eat eggs, 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. Drink two litres every day—about eight glasses.

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

If you're at the shop or takeaway place, a cheese and salad sandwich on wholemeal or multigrain bread is a good choice.

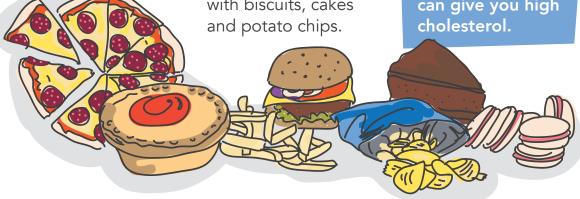
Eating unhealthy food can lead to high blood pressure, cholesterol and diabetes.

Eat less:

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

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

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



Salt. Too much salt can give you high blood pressure. You only need less than a teaspoon of salt each day.

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.

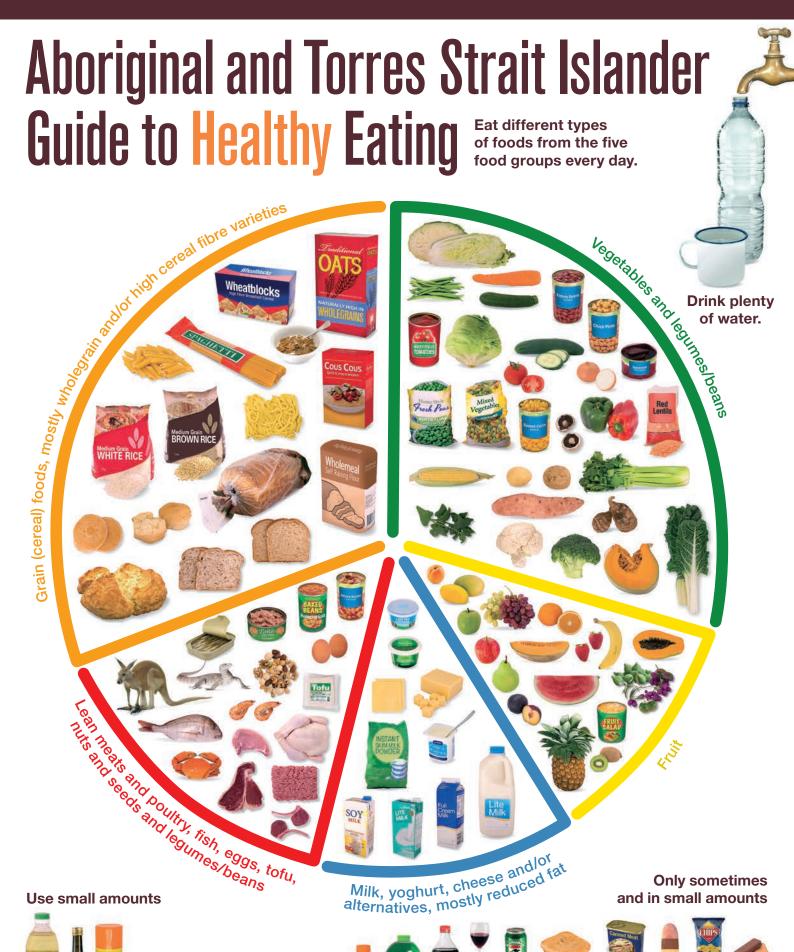
Sugar. Too much sugar can damage your arteries.

Ease up on lollies, chocolate, cakes, biscuits and ice cream.

Cut out sugary drinks - soft drinks, cordial, energy drinks, drink.



If you're unsure, speak to your dietitian about ways to eat healthy.



Be a healthy weight

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

Talk with your hospital team about:

- What a healthy weight is for you.
- Healthy eating.
- Being active.

Start by setting a small goal. Make small changes that will help you get there. If you are overweight, losing only 5% of your body weight can improve your blood pressure, cholesterol and blood sugars. Once you get there, set another goal.

Getting to a healthy weight can take time. It's 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.

Be active

Not moving enough increases your risk of stroke.

- Move as much as you can throughout your day.
 Do jobs around the house.
 Walk places instead of driving.
- Park your car further away at the shops.
- Get into activities you enjoy. Go for a walk, kick a ball around, go fishing or work in the garden. Invite family and friends to join you or join a local exercise group.
- Be active like this for at least 30 minutes every day.



I WANT TO:	STEPS:
•••••	
	•••••
BY:	

My stroke risk factors

Ask your hospital team to fill this in with you.

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
High blood pressure	 Take medicine. Get it checked regularly. Be active, be a healthy weight and don't smoke. Eat healthy food. Don't have too much salt. 		Read page 43
High cholesterol	 Take medicine. Get it checked regularly. Be active, eat healthy food, be a healthy weight and don't smoke. Eat less saturated fat. 		Read page 43
Diabetes	 Check your blood sugar when you're supposed to. Take medicine. Be active, eat healthy food, be a healthy weight and don't smoke. If you drink alcohol, follow your doctor's advice on how much you can drink. 		Read page 44
AF (Atrial Fibrillation)	 Take medicine. Be active, eat healthy food, be a healthy weight and don't smoke. 		Read page 44
Smoking	O Get help to quit smoking.		Read page 47
Alcohol	If you drink alcohol, follow your doctor's advice on how much you can drink.		Read page 47
Unhealthy food habits	Eat more food that's good for you, and less of the stuff that's not so good.		Read page 50
Being an unhealthy weight	Eat healthy food.Be more active.		Read page 53
Being inactive	Move as much as you can.Get into activities you enjoy.		Read page 53

How do I get ready to go home?

Planning to leave hospital

Your hospital team will talk with you about leaving hospital.

Think about the things you need to do when you are at home. You and your family need to know the easiest and safest way to do things.

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



Your discharge summary

A discharge summary is a piece of paper 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 need a list of your medicines too. Ask your team who will be sent a copy of your discharge summary.

You need a doctor, nurse or health worker to help you look after your health after you go home. Your local Aboriginal Health Organisation can help. Read page 65 to find your local service.

Who will help you look after your health when you get home?

After you go home, you'll need help looking after your health. You'll need a health worker to:

- Make sure you have your medicines.
- Check your blood pressure and cholesterol.
- Look after any health problems you have.

You may also want a health worker to:

- Help you be active, eat healthy food and be a healthy weight.
- Help you with ways to stop smoking.
- Help you with ways to follow your doctor's advice on how much alcohol you can drink.

There are different kinds of health workers who can help you with these things. You may have a local doctor—a GP. You may have a nurse who you see. You may have a health worker who helps you sort everything out.

Angela's Story

I'm a stroke neurologist at two hospitals in Melbourne. I visit the Northern Territory and look after people who live in regional and remote areas using telehealth—video and telephone calls.

Most people are very worried and scared after experiencing stroke. They come into the emergency department, some patients not moving normally and having trouble speaking and seeing, which can be very overwhelming. Being off Country, away from their communities and families, can add to the stress. For someone who might not have English as their first language it is incredibly scary.

What I say to people when they come into hospital is to ask a lot of questions. If your questions aren't answered in a way you understand, ask "What did you mean by that?" or ask someone else. Make sure you get the information you need to be able to understand your diagnosis and make changes to prevent further strokes.

Sometimes the questions people ask are hard for us to answer.

Questions like, "When will I go back to work?", "Am I going to be able to care for my children?"

or "Will I ever walk again?" These questions can be tough, but we will always try and give the most accurate answers.

If you feel comfortable, let people at the hospital know that you are an Aboriginal or Torres Strait Islander person. Then they can allocate an Aboriginal Liaison Officer, who can help bridge the disconnect between your culture and the culture within the hospital. Interpreters are also very important in these situations.

It is common for Aboriginal and Torres Strait Islander people when they are feeling unwell to just stay home. But it is so important that if you recognise the F.A.S.T. signs in yourself or someone else that you call an ambulance and get to a hospital straight away. As we always say, "time is brain".

It was a long journey to get to the position I am now in. I started medical school in 2007 and became qualified as a specialist after 13 years of study and training. This gave me the skills and experience to become the Aboriginal representative on the Australian Stroke Alliance board. I'm very proud of that.

Angela, Stroke Neurologist and proud Kwiambal/ Gumbaynggirr woman



For family and carers

It's important to talk to your hospital team about what life will be like at home. If you're working or caring for other people, let your team know.

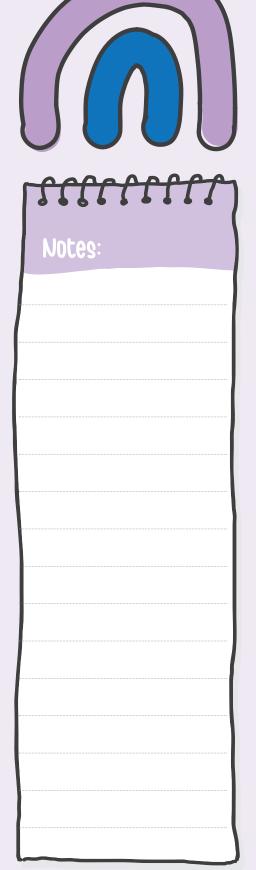
Talk about the equipment, rehab, services or appointments you need. Make sure you feel good about going home before the day arrives.

A carer is someone who looks after someone who needs help. While caring for another person shows how much we love and respect them, it can be hard. You can get support from carer's services.

Your hospital team's social worker can tell you about carer payments. Centrelink can tell you if you're eligible.

Read page 72 to find out more about help for carers.





My leaving hospital checklist

Fill this in with your hospital team.

]
My stroke	O 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 doctor or health worker.
Follow up appointments	O I know what appointments I need.O I know how these will be organised.
Services	O I know what services I need.O 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	O I know what changes I need to my home.O I know how these will be organised.
Equipment	O I know what equipment I need.O I know how this will be organised.
Rehab	O I know what rehab I need. O 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. (see below) I know to call triple zero (000) if I have any of the signs of stroke.













TIME
is critical! Call 000.

If you see any of these signs Act FAST call triple zero (000)

My appointments and services

Talk with your hospital team about appointments and services after you go home.

My appointments are:

Appointment	Date	Time	Contact details

My services are:

Service	Notes	Contact details

My local Aboriginal Health Organisation is:

Service	Notes	Contact details

How do I sort things out once I get home?

Looking after your health

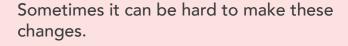
After you go home, make sure you:

- Tell anyone who helps look after your health about your stroke.
- Take your medicine as prescribed by your doctor.
- Go to all your appointments.
- See your health worker or doctor regularly.

You may need to make some changes once you get home. You may need help to:

- Be more active.
- Eat healthy food.
- Be a healthy weight.
- Stop smoking.
- If you drink alcohol, follow your doctor's advice on how much you can drink.







Talk with your health worker about exercising safely. A physiotherapist can help you be more active. Your local Aboriginal Community Controlled Health Organisation may have an exercise group you can join.



Talk with your health worker or a dietitian if you need help with healthy eating.

It can be hard to quit smoking so make sure you ask for help. Talk with your health worker about what can help you stop smoking. They can help if you need support to cut down drinking too.

Aboriginal Community Controlled Health Organisations

Your local Aboriginal Health Organisation can help you get better and be healthier.

They have doctors, nurses and allied health professionals you can see. They have healthy living, exercise and social groups. If they don't have something you need, they'll point you in the right direction.

The organisations below can help you find your local Aboriginal Health Organisation.

Australian Capital Territory

Winnunga Nimmityjah Aboriginal Health and Community Services 02 6284 6222

New South Wales

Aboriginal Health and Medical Research Council of New South Wales 02 9212 4777

Northern Territory

Aboriginal Medical Services
Alliance Northern Territory
08 8944 6666

Queensland

Queensland Aboriginal and Islander Health Council **07 3328 8500**

South Australia

Aboriginal Health Council of South Australia
08 8273 7200

Tasmania

Tasmanian Aboriginal Corporation
03 6234 0700

Victoria

Victorian Aboriginal Community Controlled Health Organisation 03 9411 9411

Western Australia

The Aboriginal Health Council of Western Australia 08 9227 1631

Getting more rehab

Your hospital team will talk with you about rehab for after you go home. After this finishes you may want an allied health professional to help you:

- Get healthy and help make sure you don't have another stroke.
- Keep going with your rehab to get better.

There are different ways to go about it:

- Aboriginal Health
 Organisations. Your local
 Aboriginal Health Organisation
 has allied health professionals
 you can see.
- Community-based rehab.
 Ask your doctor or health worker about this.

- National Disability Insurance Scheme (NDIS). If you have an NDIS plan, ask about help to get better at everyday things and reach your goals. Read page 71 to find out more.
- Medicare-subsidised sessions.
 Ask your health worker about getting a Chronic Disease
 Management Plan. There's usually a gap payment, so ask about that.
- Private health insurance.

 If you have insurance, ask what you're entitled to. There's usually a gap payment, so ask about that.

StrokeLine can help you find the best way for you. Call 1800 787 653.



Driving

Driving is a big responsibility. The laws about driving keep you and other people safe. After a stroke, you must:

- Wait. You can't drive for at least four weeks after a stroke.

 Commercial licence holders must not drive for at least three months.
- Talk to your doctor. Before you start driving again, you need medical clearance.
- You may need an occupational therapy driving assessment.
 This is to make sure you are safe to drive. Your doctor will tell you if you need one.

You need to check the rules in your state or territory. Call your state transport authority:

Australian Capital Territory

13 22 81

New South Wales

132 213

Northern Territory

1300 654 628

Queensland

13 23 90

South Australia

13 10 84

Tasmania

1300 135 513

Victoria

13 11 71

Western Australia

13 11 56

If you can't drive, community services may be able to help. You may be able to get a half-price taxi card.

StrokeLine can help you find information or services, call 1800 787 653.



Rebecca's Story

I have been an Aboriginal Brain Injury Coordinator (ABIC) since 2019, through a project called "The Healing Right Way", which I believe is the first in Australia. It is a role that was created because Aboriginal people in WA said it would help in their recovery journey.

As an ABIC my role is to support our clients who've had a stroke or a traumatic brain injury. I coordinate their care and refer them to services that help with their recovery and rehabilitation.

For many people when they come into the hospital it can be hard to understand what the doctors or nurses are saying to them. I remind people "If you don't know something, ask the doctor, the nurses, the occupational therapist, the physiotherapist or even ask me. Don't be shame to ask questions."

If our clients would like us there when they talk to the doctors, we can help them draw out the information in a way that they understand, that is also a part of what we do as an ABIC. We do a lot of support work, including emotional support.

Sometimes we have clients wanting to leave the hospital

early and go home. We try to encourage them to stay and wait until the doctors say that it's okay to go home and that it is very important to have services in place before they leave to assist in their recovery.

Once our clients are back in the community, it can be a mixed experience. Many feel happy to be back in their own home, but it can also be a challenge without the same support they had in hospital. That's why it is important to have services in place and continue the exercises and rehabilitation. My role also is to check on our clients once they return home. As an ABIC we are there to support the families of our clients and help in any way that we can, where possible.

My advice would be that it's hard at first, but you've just got to hang in there and keep going. I know there are days where you want to give up but eventually things will get better. In some cases, it won't be straight away. You've got to work hard and make the most of the services that are available to you, that's why they are there to help you.

I just want everyone I work with to know that someone cares about their rehab and recovery and wants them to get better. That's the most important part of my job.

Changes after stroke

Once you get home, you may find that you notice the things that have changed since your stroke more. You may find things are more of a problem than you expected.

Muscle spasticity.
If there are changes with your muscles, talk with your health worker. Stiff and tight muscles can cause big problems if you don't get treatment.

to worry about having another stroke. If some time has passed and it's still really bothering you, talk with your health worker.

Worrying about having

another stroke. It's normal

How you see. If how well you can see has changed,
Vision Australia can help.
Call 1300 84 74 66.

Sleep. If you're having trouble sleeping, talk with your health worker. Try to:

- Get up at the same time every day. Get out in the morning sunshine.
- Make sure your bed and bedroom is 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.

Going to the toilet.

If this is causing you trouble, **Continence Australia** can help.
Call 1800 33 00 66.



Depression and anxiety.

If you're feeling sad, down or worried, talk with your health worker. **Beyond Blue** can help too. Call 1300 224 636.



Support after stroke

Money. You may be able to recieve **Centrelink** 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 help with concession and health care cards.

1800 136 380 | humanservices.gov.au

Ask your superannuation fund if you have insurance as part of your super. If needed, ask if you can get some of your superannuation early.

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

1800 007 007 | ndh.org.au

Work. If you're having trouble at work, talk with:

- Your human resources or health and safety representative.
- Your health worker—they can find allied health services that can keep up your rehab and make things easier at work.
- Your union.

If you think you've been treated unfairly, contact your union or the **Fair Work Ombudsman**.

JobAccess help people with disabilities.

1800 464 800 | jobaccess.gov.au

Help at home. If you are under 65, call the NDIS. The NDIS helps people with a permanent and significant disability get the support they need.

1800 800 110 | ndis.gov.au

My Aged Care can help with services at home. If you are an Aboriginal and Torres Strait Islander, they can help if you are over 50 years old. If you are on a low income, homeless, or could become homeless, they can help once you are 45 years old.

1800 200 422 | myagedcare.gov.au

Independent Living Centre
Australia give advice on
equipment to make things easier
at home.

1300 885 886 | ilcaustralia.org.au

Stroke Support Groups and Choirs. Meet people, share stories and tips and have fun.

To find a group, contact **StrokeLine 1800 787 653** | **enableme.org.au**

You can also contact the Australian Aphasia Association

1800 274 274 aphasia.org.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.

For family and carers

Carer payments

Centrelink Indigenous
Call Centre

1800 136 380 | humanservices.gov.au

Supports and services

Aboriginal Community
Controlled Health Organisations
To find out more, read page 65.

Carer Gateway

Carer's services understand the ups and downs of caring. They can tell you about things to make it easier and help you get services and counselling.

1800 422 737 | carergateway.gov.au

Depression and anxiety

Family members and carers can feel sad, down or worried. They can get depression and anxiety. Read page 26 to find out more.

Never ignore feeling sad, down or worried. Talk with your doctor or health worker. Getting help can make it better.

Beyond Blue

Beyond Blue can help if you have anxiety and depression. You can call them 24 hours a day, seven days a week.

1300 224 636 | beyondblue.org.au

Lifeline

Lifeline can help if you are having a personal crisis. You can call them 24 hours a day, seven days a week.

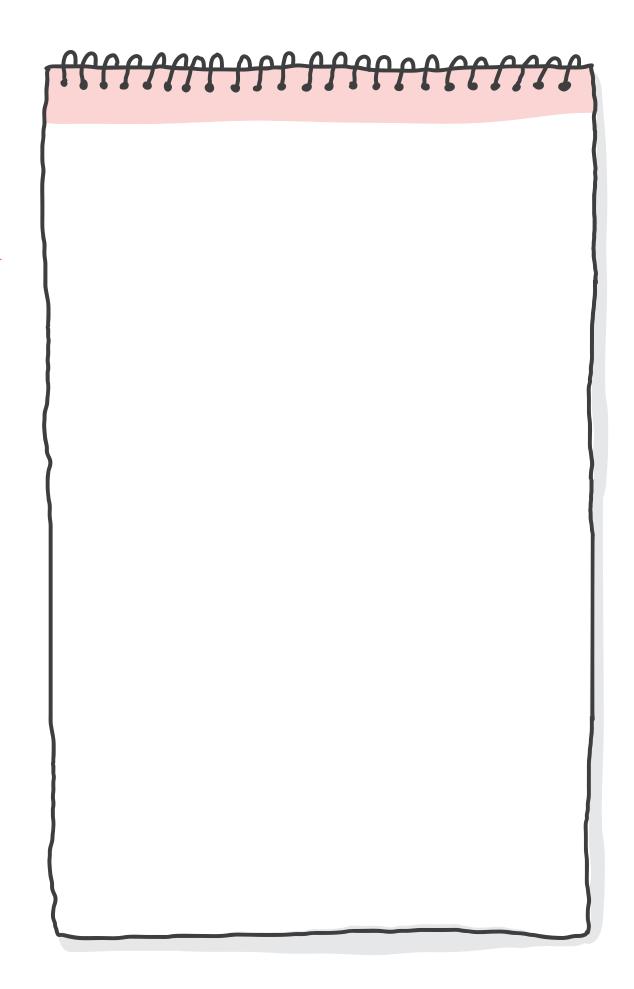
13 11 14 | lifeline.org.au

WellMob

WellMob, Healing Our Way have social, emotional and cultural wellbeing resources for you and your family.

wellmob.org.au

PPPPPPPPPPPPPPPPPPPPPPPPPPPPPPPPPPPPPP
Notes:







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.
- **\cong Know your numbers** check your health regularly.
- Stay informed keep up-to-date and share our message.

Contact us

- **StrokeLine 1800 787 653**
- ☐ strokefoundation.org.au
- /strokefoundation
- @strokefdn
- © @strokefdn