My Stroke Journey
A resource for stroke survivors and their carers

Keep this booklet with you in hospital
About the Stroke Foundation

The Stroke Foundation is a national charity that partners with the community to prevent, treat and beat stroke. We stand alongside stroke survivors and their families, healthcare professionals and researchers. We build community awareness and foster new thinking and innovative treatments. We support survivors on their journey to live the best possible life after stroke. We are the voice of stroke in Australia and we work to:

› Raise awareness of the risk factors, signs of stroke and promote healthy lifestyles.
› Improve treatment for stroke to save lives and reduce disability.
› Improve life after stroke for survivors.
› Encourage and facilitate stroke research.
› Advocate for initiatives to prevent, treat and beat stroke.
› Raise funds from the community, corporate sector and government to continue our mission.

Visit strokefoundation.org.au for more information.
Welcome to the Stroke Foundation’s “My Stroke Journey”

This pack provides stroke information to support your recovery. It belongs to you. Keep it with you in hospital so your stroke team can go through the information with you. You can also keep any other information you are given in the folder.

This book contains information about stroke and how stroke can impact on you and your family and friends. It provides details on hospital processes and rehabilitation, as well as information to help prepare you and your carer and family for leaving hospital. At the back of the book you will find a Strokesaurus with the definitions for common medical terms.

This is a book for you and your stroke team to work through together. My Stroke Journey will help ensure you have a complete care plan for when it’s time to leave hospital.

A care plan describes the care you will receive after you leave hospital. The plan includes rehabilitation goals, lifestyle modifications and medicines needed to manage risk factors, any equipment you need, follow up appointments and contact details for ongoing support services available in the community.

Together with your stroke team, you can write in the care plan sections throughout My Stroke Journey. You will find the care plan sections highlighted in light blue within this book. Each care plan section is also listed in the table of contents on the next page.

Call StrokeLine 1800 STROKE (1800 787 653)

Visit enableme – our online tool to aid stroke recovery. enableme.org.au

This symbol indicates there is a fact sheet available on this topic. Ask a member of your stroke team for a copy or visit enableme.org.au

This symbol indicates a helpful tip or website on this topic.
# Table of contents

## About stroke
- What is a stroke? 6
- Types of stroke 7
- How a stroke can affect you 11
- What to expect in the first few days 16
- Early treatment for stroke 17
- Admission to hospital 18
- Who will be involved in my care while in hospital? 21
- Family meetings 29

## Reduce your risk
- How do I reduce my risk of having another stroke? 30
- What else can I do to control my risk? 37
- How do I know if I’m having another stroke? 39

## Rehabilitation and leaving hospital
- Rehabilitation after stroke 40
- Goal setting 42
- The next step: planning to leave hospital 44

## Carer information
- Becoming a carer 49
- Carer emotions 50

## Further information
- StrokeLine 51
- enableme 52
- Where to get more help after stroke 54
- Accessing information online 60
- Stroke Foundation fact sheets 61
- Strokesaurus (medical terms) 62

## Care plan pages
- Care plan contents
  - The type of stroke you had 8
  - Stroke team members 22
  - What are my risk factors? 38
  - Steps to setting your goals 43
  - Checklist for leaving hospital 46
  - Appointments and services 47
What is a stroke?

A stroke happens when the blood supply to the brain is interrupted. Blood is carried to the brain by blood vessels called arteries. The picture below shows the different arteries in the brain. Blood contains oxygen and important nutrients for your brain cells. Blood may be interrupted or stop moving through an artery because the artery is blocked (ischaemic stroke) or bursts (haemorrhagic stroke). When brain cells do not get enough oxygen or nutrients, they die. The area of brain damage is called a cerebral infarct.

Brain cells usually die shortly after the stroke starts. However, some can last a few hours if the blood supply is not cut off completely. If the blood supply can be returned in the minutes and hours after the stroke, some of these cells may recover. If not, they will also die.
Types of stroke

1. A blocked artery

A stroke that is caused by a blood clot is called an ischaemic stroke (is-key-mick).

In everyday life, blood clotting is beneficial. When you are bleeding from a wound, blood clots work to slow and eventually stop the bleeding. In the case of stroke, however, blood clots are dangerous because they can block arteries and cut off blood flow.

There are two ways an ischaemic stroke can occur:

- **Embolic stroke**
  If a blood clot forms somewhere in the body (usually the heart) it can travel through the bloodstream to the brain. Once in the brain, the clot travels to a blood vessel that’s too small for it to pass through. It gets stuck there and stops blood from getting through. These kinds of strokes are called embolic strokes.

- **Thrombotic stroke**
  As the blood flows through the arteries, it may leave behind cholesterol-laden ‘plaques’ that stick to the inner wall of the artery. Over time, these plaques can increase in size and narrow or block the artery and stop blood getting through. In the case of stroke, the plaques most often affect the major arteries in the neck taking blood to the brain. Strokes caused in this way are called thrombotic strokes.

2. A bleed in the brain

Strokes caused by a break in the wall of a blood vessel in the brain are called haemorrhagic strokes (hemm-orr-ragic).

This causes blood to leak into the brain, again stopping the delivery of oxygen and nutrients.

Haemorrhagic strokes can be caused by a number of disorders which affect the blood vessels, including longstanding high blood pressure and cerebral aneurysms.

An aneurysm is a weak or thin spot on a blood vessel wall. The weak spots that cause aneurysms are usually present at birth. Aneurysms develop over a number of years and usually don’t cause detectable problems until they break.
A stroke can happen in two main ways. Either there is a blood clot or plaque blocking an artery in the brain, or a blood vessel in the brain breaks or ruptures causing a bleed in the brain.

An arteriovenous malformation (AVM) is a tangled mass of blood vessels (arteries and veins). It can occur anywhere in the body including the brain. An AVM is usually present at birth. It may be that as you get older the blood vessels get bigger and weaker. If the AVM is located in the brain and the blood vessel walls burst then you will have a haemorrhagic stroke.

There are two types of haemorrhagic stroke: subarachnoid and intracerebral.

These two terms refer to areas of the brain where the stroke has occurred.

In a subarachnoid haemorrhage, bleeding occurs under the thin, delicate membrane surrounding the brain.

In an intracerebral haemorrhage, bleeding occurs within the brain itself.

The type of stroke you had:

- Ischaemic stroke (embolic and thrombotic)
- Haemorrhagic stroke (subarachnoid and intracerebral)
I don’t remember much of the first few days. One minute I was making a cup of tea, the next I was waking up in hospital with people asking me questions. My husband had seen me collapse and he called the ambulance. They got me straight to hospital. They did the first scan and told him they wanted to give me the clot-busting drug. It must have been so nerve wracking for him, having to make such a quick decision.

After a nervous few hours, the doctors told him they were quietly confident. He practically slept there for the next few days, sitting with me, waiting for test results, and talking with the team. I was able to go home after a few weeks. I still have trouble getting my words out when I’m tired. I’m very glad my husband was able to keep a clear head throughout it all.

Linda, stroke survivor

Join the free online community for stroke survivors, their families and friends at enableme.org.au
Different function areas of the brain

Frontal lobe
- Motor control
- Personality
- Concentration
- Problem solving
- Planning

Parietal lobe
- Sensory areas of touch, pain and temperature
- Spatial orientation and information processing
- Understanding speech
- Language expression

Temporal lobe
- Hearing
- Memory of hearing and vision

Brain stem
- Breathing
- Heart rate control
- Consciousness, alertness, wakefulness
- Swallowing
- Blood pressure
- Sweating

Occipital lobe
- Vision recognition
- Focus of the eye

Cerebellum
- Balance
- Coordination of movement
- Posture
- Fine motor skills
How a stroke can affect you

There are several factors that impact on recovery after stroke. These factors include:

- type of stroke.
- location of the blocked or burst artery.
- which area of the brain is damaged.
- how much brain tissue is permanently damaged.
- your general health before the stroke.
- your level of activity before the stroke.

Each half of the brain is divided into areas called lobes. The different areas control different functions of your body. These functions include how you move your body, receive sensory messages (such as touch, sight or smell), use language and think. Because different arteries supply different areas of the brain, where the brain is damaged will determine which functions are affected. The left half of the brain (left hemisphere) controls most functions on the right side of the body, while the right half of the brain (right hemisphere) controls most functions on the left side.

Some of the problems that people may have after a stroke include:

- Weakness on one side of the body (in your arm and/or leg) – this might cause difficulty balancing, standing, walking or using your arm or hand. See the Upper limb management and Mobility and exercise fact sheets for more information.
- Controlling or coordinating movements – this can be due to difficulties planning the movement (called apraxia or dyspraxia). This might cause difficulty standing or sitting without falling or leaning to one side, or difficulty using your arm/s. See the Mobility and exercise fact sheet for more information.
- Sensation – changes in your ability to feel touch, pain or temperature. You may have numbness, pins and needles or odd sensations in the affected area.
- Communication – difficulty with language, such as talking, understanding what people are saying, reading, writing or a combination of these. Also called aphasia or dysphasia. See the Communication fact sheet for more information.
- Slurring words – difficulty with talking. This can be because the muscles used to speak, such as lips and tongue, are weak (called dysarthria). This can also be because of difficulties planning lip and tongue movement (called verbal dyspraxia).

Neuroplasticity

Research now indicates the brain has the ability to change. This ability is called neuroplasticity. After a stroke, pathways in the brain can change so unaffected parts of the brain can take over the job of affected areas. Through this process, recovery can occur after a stroke.
Swallowing – loss of control or weakness of the muscles that help you to swallow can mean difficulty swallowing foods, drinks or your own saliva. Also called dysphagia. See the Swallowing problems and Diet fact sheets for more information.

Thinking and memory – for example, you may have poor attention, difficulty remembering things, planning or organising things or solving everyday problems. Also called cognition. See the Thinking and perception fact sheet for more information.

Vision and perception – some people have double vision (seeing two of everything) after a stroke. Some people have difficulty seeing things on one side or perceiving how close objects are. See the Vision loss fact sheet for more information.

Ignoring one side – difficulty recognising one side of your body or the environment around you. Also called neglect. See the Thinking and perception fact sheet for more information.

Continence or toileting – difficulty controlling your bladder and bowel movement, or difficulty getting to the toilet in time. This may be because of other difficulties from the stroke (like sensing when you need to empty your bladder or bowels, or being able to walk to the toilet). See the Incontinence fact sheet for more information.

Pain – pain may be constant or it may come and go. Pain will usually be on the side of the body affected by the stroke, however any part of the body may become painful after a stroke. Some people experience headaches after their stroke. See the Pain management fact sheet for more information.

Sexual activity – feeling worried about having sex or physical changes that may make sexual activity difficult. See the Sex and relationships fact sheet for more information.

Appetite – not wanting to eat or drink as much as you used to. See the Diet fact sheet for more information.

Behaviour and personality – difficulty with insight or acknowledging that you have difficulties because of the stroke. Poor safety and judgement may lead to behaviour being impulsive or inappropriate to a particular situation. Some people experience personality changes after a stroke. Some laugh or cry uncontrollably even though they don’t feel happy or sad (this is called emotional lability). See the Emotional and personality changes fact sheet for more information.

Depending on the location and size of your stroke, you may have one or more of these difficulties.

Ask your stroke team for any relevant fact sheets or visit enableme.org.au
Emotions

It’s very normal to experience strong emotions after a stroke. You may feel angry that you had a stroke. You may feel anxious about why you had a stroke or about what is happening to you. You may feel frightened about the future. You may also feel gratitude at survival, hope for recovery and love for family and friends.

Emotional reactions will usually get easier with time. However after your stroke you may experience more long-lasting emotional difficulties, including depression and anxiety. These are common at any stage after a stroke and can be treated.

Another common impact of stroke is emotional lability, where you have emotional responses that don’t seem to make much sense or are out of proportion. Sometimes you may cry or laugh uncontrollably, even though you do not know why you are doing it. As we generally pride ourselves on keeping our emotions in check, especially in social situations, this effect of stroke can be very challenging.

Being aware of anything that triggers emotional lability can help. This will be different for everyone. Things to look out for include tiredness, stress, anxiety and noisy, overcrowded environments. Being around emotional people, situations or events can trigger lability, as can being put under pressure. See the Emotional and personality changes and the Depression and anxiety fact sheets for more information.

Fatigue

Fatigue is very common after stroke. Fatigue is a feeling of weariness, tiredness or a lack of energy. Fatigue after stroke is not improved by rest, so it is not like typical tiredness. It can make it more difficult for you to participate in rehabilitation and in everyday activities.

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

The signs of fatigue are not always obvious to other people and so they may not understand how you are feeling. If you think fatigue may be an issue for you, ask your treating team to speak to you and your family about it.

There are lots of things that you can do to manage fatigue. See the Fatigue fact sheet for more information.
Imagine waking up and finding that you can’t utter one word. A few weeks after the stroke I managed to say “hello”. Finding the word I wanted to say was challenging enough, but working out how to pronounce it was even more testing. When I did manage to speak the words, the ones in my head were often different from those I was verbalising. I couldn’t trust what I was saying.

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

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

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

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

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

Claire, stroke survivor

Join the free online community for stroke survivors, their families and friends at enableme.org.au
What to expect in the first few days

Early assessment of stroke

You will usually be admitted to hospital through the emergency department. The doctors will do some tests to:

› make sure the symptoms are definitely due to stroke.
› work out the type of stroke.
› find out what area of the brain was affected.
› work out how severe the impact of the stroke was on the brain.
› if possible find out and start treating the cause of the stroke.

Everyone will need a different set of tests. Common tests include:

Brain scans:

› Computerised tomography (CT scan) and magnetic resonance imaging (MRI).
› These tests take pictures of your brain that show areas of damage and swelling.
› Either a CT scan or MRI should be done urgently within the first 24 hours after a stroke. This is to work out the type of stroke (ischaemic or haemorrhagic).
› They may be repeated later to see how much of the brain has been affected by the stroke, or if you are getting worse.

Heart tests:

› An electrocardiogram (ECG) is a test for abnormal heart rhythm or heart disease. This test is recommended for all stroke patients.
› An echocardiogram is an ultrasound to check for a clot or enlargement of a chamber in your heart.

Other tests that may be performed in the early days in hospital include:

› Transcranial doppler (TCD): This is an ultrasound that measures the speed of the blood flow in the brain arteries. This can help identify areas of slow blood flow in the brain.
› Cerebral angiogram: a catheter is placed in an artery and used to inject a special dye (contrast material). X-ray images are taken to see how the dye moves through the artery and blood vessels of the brain. This dye helps show any blockages in blood flow.
› Carotid duplex (also called a doppler): an ultrasound that looks at neck arteries. It can tell if these arteries are narrow or partially blocked.
Blood tests:
- There is no specific blood test for stroke.
- Blood tests are used to rule out other medical conditions and help the doctors decide the best treatment.
- The most common blood tests will measure:
  - the clotting ability of your blood (international normalised ratio or INR)
  - fasting lipids (cholesterol) level
  - renal (kidney) function
  - glucose (blood sugar) levels
  - electrolytes balance (salt levels)
  - leukocyte (white blood cell) count
  - haematocrit (iron) levels
  - erythrocyte sedimentation rate and c-reactive protein (as measures of inflammation in the body)
- Urine tests or chest X-rays may also be done to check for infection or other disease.
- Regular observations will also be taken to monitor blood pressure, pulse (heart rate), temperature, blood sugar levels, oxygen levels and breathing pattern.

Early treatment for stroke
There is no medical treatment that will repair the brain damage from the stroke.

To minimise the damage caused by an ischaemic stroke, some people may be suitable for thrombolysis and endovascular clot retrieval.

Thrombolysis is the process where rt-PA is administered. rt-PA is a clot-busting drug that breaks down a blood clot. This allows blood flow to return to the brain.

Endovascular clot retrieval or intra-arterial thrombectomy is another treatment used to return blood flow to the brain, often in conjunction with thrombolysis. After the clot has been pinpointed by a brain scan, a tiny tube is fed into the blocked blood vessel, usually inserted through an artery in the leg and fed up through the body into the brain. A wire stent or suction device captures the blood clot and allows it to be pulled back out.

Thrombolysis and endovascular clot retrieval are procedures that are not suitable in every case. This is because:
- The procedures can only be performed if you have had a stroke caused by a blood clot (ischaemic stroke). You need an urgent CT scan to check the type of stroke you have had.
- Thrombolysis and endovascular clot retrieval must be performed within a few hours after your stroke. The stroke team will decide whether you are likely to benefit from these procedures and will discuss this with you.
Although thrombolysis and endovascular clot retrieval improve your recovery after stroke, they can also cause bleeding in the brain. Therefore, it can be risky for some people.

Thrombolysis and endovascular clot retrieval should be performed by a doctor who is trained in these techniques. Ideally they should be performed in a hospital with a stroke unit or an organised stroke service. Therefore these procedures are not performed at all hospitals.

**Reducing the risk of stroke**

There are other early treatments you might receive to help you recover. For example, aspirin should be taken in the first 48 hours after stroke by all who had a stroke due to a clot (ischaemic stroke). Aspirin may also be taken long term to prevent another stroke.

**Admission to hospital**

All people with stroke should be admitted to hospital. They should be treated in a stroke unit. A stroke unit is a set area in a hospital where a specialised stroke team provide early and active treatment after stroke. Some people may be moved from smaller hospitals to larger hospitals that have a stroke unit.

Care will be provided by a range of health professionals called the stroke team. These health professionals are trained in the management of stroke.

**Early progress**

Your health professionals will work with you to ensure you make the best recovery possible. Everyone progresses differently in the first few days after a stroke. Some people will make a good recovery quite quickly after their stroke, whilst other people may make slower progress. Some people will suffer complications after their stroke, however most people will survive and go on to make improvements in their function.

As with any serious medical event, it’s very normal to feel strong emotions after a stroke, even if you make a good recovery. Talk to your team, family and friends about how you are feeling.

**Your health professionals will work with you to ensure you make the best recovery possible. Everyone progresses differently in the first few days after a stroke.**
You can use this page to take notes and to keep track of tests and procedures.

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

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

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

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

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

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

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

Emma, stroke survivor
Who will be involved in my care while in hospital?

The stroke team

The stroke team is a group of health professionals who will work with you to treat the different problems that can occur after a stroke. Listed on the next pages are the types of health care workers who make up a stroke team. Each stroke team is different. Some teams do not have all the members listed. Some stroke teams have other members not listed here, such as leisure therapists, orthoptists and therapy assistants. Talk to a member of your team if you think you need to see someone who has not been made available to you.

The team will work with you and your family while you are in hospital and sometimes when you go home. It can be helpful to write down the names and contact details of your stroke team members. You may have questions or problems you would like to discuss.

Remember you and your family are also important members of the team. You need to work together with the health professionals to manage the impact of your stroke.

› Remember you and your family are also important members of the team. You need to work together with the health professionals to manage the impact of your stroke.
### Stroke team member

**Doctor: consultant**

The consultant is the doctor in charge of your hospital care. He or she is responsible for making sure the team knows what has happened to you and why.

The consultant manages the medical problems of the stroke as well as any other past medical condition such as diabetes, high blood pressure or urinary infections. Your consultant may be a **neurologist**, **rehabilitation physician** or **geriatrician** or may specialise in another area of medicine.

<table>
<thead>
<tr>
<th>Questions you might ask your health professional</th>
<th>Name of your health professional and contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td>What type of stroke did I have?</td>
<td></td>
</tr>
<tr>
<td>What area of my brain was damaged by my stroke?</td>
<td></td>
</tr>
<tr>
<td>How will the stroke affect me?</td>
<td></td>
</tr>
<tr>
<td>What medication am I taking and why?</td>
<td></td>
</tr>
<tr>
<td>Can I drive again?</td>
<td></td>
</tr>
</tbody>
</table>

**Doctors: registrar and residents**

The registrar and resident report to the consultant. They are responsible for your day to day care. You may see these doctors every day. They coordinate assessments and management under the direction of the consultant.

<table>
<thead>
<tr>
<th>Questions you might ask your health professional</th>
<th>Name of your health professional and contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the name of the test or treatment that I’m having?</td>
<td></td>
</tr>
<tr>
<td>Why is that test being done?</td>
<td></td>
</tr>
<tr>
<td>Who will explain the results to me and my family?</td>
<td></td>
</tr>
</tbody>
</table>
## Stroke team member Questions you might ask your health professional Name of your health professional and contact details

<table>
<thead>
<tr>
<th><strong>Doctors: general practitioner</strong></th>
<th><strong>Questions you might ask your health professional</strong></th>
<th><strong>Name of your health professional and contact details</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Your general practitioner (GP) is an important member of the team who will work with you when you go home. In some parts of Australia a GP might look after you in hospital. Your GP will work with you to reduce the chances of another stroke. This could be with medication and lifestyle changes.</td>
<td>What is this medication for? How long do I have to take this medication for? What are the side effects of this medication? How can I reduce my chances of having another stroke?</td>
<td></td>
</tr>
<tr>
<td>Your GP can also work with you if you feel sad or depressed or are having trouble getting used to life after stroke. Your GP may also refer you to other health professionals or services that can help you.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Nurses</strong></th>
<th><strong>Questions you might ask your health professional</strong></th>
<th><strong>Name of your health professional and contact details</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses provide 24-hour care while you are in hospital. They take your observations (blood pressure, pulse rate, temperature). They will help you if you have any bladder or bowel problems. They check your progress and talk with your doctor and other team members. Nurses help you with everyday activities like showering, eating, going to the toilet and moving around your room. Community nurses can provide care such as assistance with medications, injections or wound care when you are back at home.</td>
<td>What is my blood pressure? Can someone help me each day with meals? How do I improve my incontinence? What can I do to be more independent on the ward?</td>
<td></td>
</tr>
</tbody>
</table>
# Stroke team member

## Stroke care coordinator/discharge coordinator

A stroke care coordinator will help match your needs with members of the stroke team while you are in hospital. They help plan your discharge from hospital or transfer to a rehabilitation ward. They may help organise family meetings between the stroke team and family. Not all hospitals have this team member.

<table>
<thead>
<tr>
<th>Questions you might ask your health professional</th>
<th>Name of your health professional and contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which members of the stroke team are helping me?</td>
<td></td>
</tr>
<tr>
<td>Do I need to see any other members of the stroke team?</td>
<td></td>
</tr>
<tr>
<td>When are we having a family meeting?</td>
<td></td>
</tr>
<tr>
<td>Where will I be going next?</td>
<td></td>
</tr>
<tr>
<td>What help do I need when I go home?</td>
<td></td>
</tr>
</tbody>
</table>

## Occupational therapist

An occupational therapist (OT) will help you to manage day to day tasks such as dressing and showering. They can help people return to work and/or leisure activities. OTs can also help with thinking or memory problems, vision and perception problems, and hand or arm problems. If needed, your OT may do a home visit to assess your needs and organise equipment while you are still in hospital. This can make it easier and safer for you to get around your house.

You may need to be referred to a specialist OT who will complete a driving assessment.

- See the Driving fact sheet for more information.

<table>
<thead>
<tr>
<th>Questions you might ask your health professional</th>
<th>Name of your health professional and contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td>What exercises can I do to help improve my arm or hand?</td>
<td></td>
</tr>
<tr>
<td>How can my family help?</td>
<td></td>
</tr>
<tr>
<td>What can I do to help manage my memory problems?</td>
<td></td>
</tr>
<tr>
<td>Can you help make sure my home environment is safe and I have equipment I need at home?</td>
<td></td>
</tr>
<tr>
<td>What do I need to do to get back to driving?</td>
<td></td>
</tr>
<tr>
<td>Will I be able to get back to work? How?</td>
<td></td>
</tr>
<tr>
<td>Is there anything about my stroke that will affect my sex life?</td>
<td></td>
</tr>
<tr>
<td>How can I get back to my hobbies?</td>
<td></td>
</tr>
<tr>
<td>Stroke team member</td>
<td>Questions you might ask your health professional</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td><strong>Physiotherapist</strong></td>
<td>Will I need an aid to be able to get around my home safely?</td>
</tr>
<tr>
<td></td>
<td>What exercises can I do to help my recovery? How often should I do these exercises?</td>
</tr>
<tr>
<td></td>
<td>How can my family help me with my exercises and recovery?</td>
</tr>
<tr>
<td></td>
<td>How important is it to stay active after my stroke?</td>
</tr>
<tr>
<td></td>
<td>How can I get regular exercise if my leg/arm is weak from the stroke?</td>
</tr>
<tr>
<td></td>
<td>Can you show me how I can get off the floor myself if I fall?</td>
</tr>
<tr>
<td>Speech pathologist</td>
<td>What needs to happen before I can drink normal fluids again?</td>
</tr>
<tr>
<td></td>
<td>How can my family member help me to be safe when swallowing my food?</td>
</tr>
<tr>
<td></td>
<td>How can my family member help me to communicate?</td>
</tr>
<tr>
<td></td>
<td>How does a communication book/device work?</td>
</tr>
<tr>
<td></td>
<td>Are there any exercises I can do to practise my speech?</td>
</tr>
</tbody>
</table>

The speech pathologist may assess you to see if you can swallow safely after a stroke. They may recommend a modified diet to help you eat and drink safely. They may also give you exercises to strengthen the muscles used to swallow. Speech pathologists will also help if you have trouble speaking or understanding what is said to you. They will give you exercises and tips to communicate with your family and friends.

See the Swallowing problems, Diet and Communication fact sheets for more information.
<table>
<thead>
<tr>
<th>Stroke team member</th>
<th>Questions you might ask your health professional</th>
<th>Name of your health professional and contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dietitian</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A dietitian will help you if you are having problems eating enough food because of swallowing difficulties or poor appetite. They will check your nutritional needs and order special fluids or meals if required. They can also give you advice about healthy foods and reading food labels. This can help reduce your risk of another stroke.</td>
<td>I can’t swallow normal food at the moment – what else can I eat?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Can my family bring food in for me from home?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What can I change in my diet to reduce the risk of stroke?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social worker</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A social worker can help with the emotional, social and financial impact of stroke. They can provide support and counselling for you and your family. They also provide information about discharge planning, community services and government payments and allowances.</td>
<td>I’m feeling very sad and worried, is this normal and what can I do?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Can you tell me about payments and allowances I might be eligible for?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are my options if I feel I can’t manage at home?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>My family member can’t make decisions or manage their finances, what happens now?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke team member</td>
<td>Questions you might ask your health professional</td>
<td>Name of your health professional and contact details</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------</td>
</tr>
</tbody>
</table>
| **Psychologist (or clinical psychologist)** | I’m feeling quite stressed about how my family and I will manage at home. Can you help me?  
My mood has been low since my stroke. What can I do?  
I’m feeling anxious about having another stroke. What can I do? | ________ |

A psychologist or clinical psychologist may help if you or your family is having trouble getting used to life after stroke or if you are depressed or anxious. A clinical psychologist can also help if the whole family is having trouble getting used to life after stroke.

| **Neuropsychologist** | I don’t feel like myself since the stroke. Why?  
Will the changes in my thinking and personality improve?  
My family member thinks I now do things that are dangerous. What can we do?  
How will my thinking and memory problems affect going back to work? | ________ |

A neuropsychologist may work with you if you are having trouble with memory, thinking or behavioural problems. They may work with an occupational therapist or your family member in developing practical strategies to help with these problems after stroke. A neuropsychologist may also provide advice to other team members on how the stroke has affected your ability to make decisions.

| **Pharmacist** | Can you tell me why I am taking each medication? How long should I take each medication for?  
Are there any side effects I should be aware of?  
When should I visit my doctor for further prescriptions?  
Are there any types of food or drink, or other medications I should avoid?  
What do I do if I forget to take a dose of my medication?  
Who should I speak with if I have questions about my medications after I leave hospital? | ________ |

The pharmacist will work closely with the medical and nursing team to make sure your medication is suitable and safe for you to take. They will discuss your medications and possible side effects with you and can provide a medication list on discharge. The pharmacist can also discuss strategies to reduce your risk of another stroke, for example giving you advice about ways to help you stop smoking.
You can use this page to take notes

_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
Family meetings

Early and regular communication between you, your family and the stroke team is very important.

A family meeting is a formal meeting between the family and members of the stroke team. Family meetings may be organised by the stroke care coordinator, social worker or another member of the team. You or a member of your family can also request a family meeting.

Family meetings are used to:

› Keep you and your family up to date.
› Plan and make decisions about treatment, goals and next steps.
› Plan hospital discharge or transfer to another care facility.
› Provide your family with a chance to ask questions of any member of the stroke team.

You may feel anxious about a meeting with the whole stroke team. You may get a lot of information in a short period of time. Some helpful hints for family meetings are:

› Prepare a list of questions you would like answered.
› Share the load by taking a friend or family member along to listen and support you. This can be face-to-face or by phone.
› Take notes or ask the team for a written summary if you need it.
› Ask for an interpreter if needed.

Decision making

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

Enduring powers of attorney are legal documents that appoint a decision maker should someone become unable to make decisions for themselves. The power given ‘endures’. This means it continues even if and when the person loses capacity to make their own decisions.

Powers of attorney can only be made by someone who has legal capacity. This means they fully understand the nature and effect of the document they are completing and the nature and extent of their estate.

Where there is no enduring power of attorney, there is a legal body in each state that can appoint a decision maker. This is only done where there is a need to do so, and when it is in the best interests of the person with the disability. A Guardian can be appointed to make lifestyle or personal decisions, while an Administrator can make financial decisions.

Your social worker and treating team can provide advice about decision making.
How do I reduce my risk of having another stroke?

Now you have had a stroke, your risk of having another stroke is higher. Understanding and managing your risk factors is important. This will help lower your risk of having another stroke. Many stroke survivors worry about what will happen if they have another stroke. Taking positive action will also help you feel more in control.

What are the risk factors for stroke?

Risk of further stroke is influenced by a number of factors. The more risk factors you have the higher your chance of having a stroke. There are some stroke risk factors you cannot do anything about. These include:

› Age – the older you get the greater your risk of stroke.
› Gender – stroke is more common in men.
› A family history of stroke – having a parent or sibling who has had a previous stroke.
› Previous stroke or transient ischaemic attack (TIA). Sometimes called a mini-stroke, a TIA is a warning a stroke may happen soon.

However there are a number of risk factors for further stroke you can do something about. These are the modifiable risk factors and include:

High blood pressure

High blood pressure (hypertension) – is the most important known risk factor for stroke.

Blood pressure is a measure of the force with which blood presses on the walls of your arteries as it is pumped around your body. This pumping action is driven by your heart.

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

High blood pressure puts a strain on blood vessels all over the body including arteries to the brain. This means the heart has to work much harder to keep the blood circulation going.

High blood pressure can lead to a stroke in several ways:

› it damages blood vessel walls making them weaker.
› it can speed up common forms of heart disease.
› it can cause blood clots or plaques to break off artery walls and block a brain artery.

Blood pressure is expressed with two numbers:

| 120 | Systolic pressure – The force your blood puts on the blood vessel walls as your heart pumps. |
| 80  | Diastolic pressure – The force your blood puts on blood vessel walls when your heart is resting between beats. |
Control this risk by:

Knowing your blood pressure and keeping it down.

You can control your blood pressure by changing your diet and lifestyle (particularly through regular exercise and maintaining a healthy weight).

Everyone who has had a stroke should be on blood pressure lowering medication. This is even if you have ‘normal’ blood pressure.

The lower your blood pressure, the lower your risk of stroke.

Your doctor can help you to regularly check your blood pressure.

High cholesterol

High cholesterol (hyperlipidaemia or dyslipidaemia) – contributes to blood vessel disease, which often leads to stroke.

Cholesterol is a soft, waxy fat that is made by the body. We also absorb some cholesterol from foods we eat such as eggs, meats and dairy products.

The main cause of high cholesterol is a diet high in saturated fats (fats from animal foods). High cholesterol may also be hereditary.

There are two types of cholesterol:

› Low density lipoprotein (or LDL) is the ‘bad’ cholesterol that builds up on the artery walls
› High density lipoprotein (or HDL) is the ‘good’ cholesterol. It is called the good cholesterol because it removes cholesterol from the blood stream. It takes cholesterol from the cells in our body to the liver where it is broken down and removed safely from our body.

The ratio of good cholesterol to bad cholesterol is the key measurement of your stroke risk. The more HDL you have the lower your risk for stroke. The more LDL that you have, the greater your risk for stroke.

Control this risk by:

Speaking to your doctor about your current cholesterol level and what you should aim for to reduce your risk of a further stroke.

Medication, diet changes and exercise can all reduce your cholesterol.

If you had an ischaemic stroke, your doctor should prescribe medication to lower your cholesterol level.

Diet changes are also important, so eat foods low in saturated fat (lean meats and dairy products that are mostly reduced fat).

Dietitians are available in hospital and in the community who can help you to lower the amount of bad cholesterol in your diet.

Call StrokeLine 1800 STROKE (1800 787 653) or visit enableme.org.au to find out how to access community-based dietitians.

Regular physical activity is also important.
They said my stroke was mild. I lost a bit of strength in my left hand for a while. But with the exercises the therapists gave me to do at home it was back to normal after about a month. The doctor told me I’d have to wait a month before going back to driving and recommended I do light duties at work for two weeks after that.

It gave me the fright of my life being told I’d had a stroke! I didn’t think I was that unhealthy. But I was smoking, carrying a few too many kilos and they said I had high cholesterol. Now I have to take medication everyday and I’ve given up the smokes. It’s been hard but not as hard as the thought of having another stroke! I reckon I’ve been given a second chance with my health and I don’t want to run the risk of having another stroke.

Robert, stroke survivor

Join the free online community for stroke survivors, their families and friends at enableme.org.au
Smoking
Smoking doubles your risk of stroke. The more you smoke the greater your risk of stroke.

Smoking increases your risk of further stroke by increasing blood pressure and reducing oxygen in the blood. Smoking also increases the stickiness of the blood. This further increases the risk of blood clots forming.

Tobacco smoke contains over 4,000 toxic chemicals which are deposited on the lungs or absorbed into the bloodstream. Some of these chemicals damage blood vessel walls, leading to atherosclerosis (narrowing and hardening of the arteries). This increases the chance of blood clots forming in the arteries to the brain and heart.

Control this risk by:
Knowing it is never too late to stop smoking. Five to fifteen years after quitting, a person’s risk for stroke becomes similar to someone who has never smoked. There is a lot of help available if you want to stop smoking. This includes telephone counselling, smoking cessation clinics, nicotine replacement therapy products and medication.

Quitline provides information and support. Call 13 78 48 or www.quitnow.gov.au

Obesity
Obesity, being overweight or too much body fat can contribute to high blood pressure and high cholesterol. It can also lead to heart disease and type 2 diabetes.

A healthy waist measurement should be less than 80 cm in women and less than 94 cm in men. These measurements are recommended for people from Caucasian backgrounds. If you’re from a different cultural background, speak with your doctor about your risk. You can find more information from the Healthy Weight Guide: www.healthyweight.health.gov.au

If you are having difficulties keeping your weight within recommended levels ask a doctor or dietitian for help.

Poor diet and lack of exercise
Being inactive, having a poor diet or both can increase your risk of high blood pressure, high blood cholesterol, diabetes, heart disease and further strokes.

Healthy eating is important for reducing your risk of further stroke. It impacts on a number of risk factors. For example, a lot of salt in the diet increases blood pressure.

Regular physical activity can reduce your risk of stroke.

Control this risk by:
› Enjoying a balanced diet.

The Australian Dietary Guidelines recommend you eat:
› Plenty of vegetables. Choose different types and colours. Eat legumes (peas, lentils and beans).
› Fruit.
› Grain or cereal foods. Choose wholegrain and high-fibre types of bread, cereal, rice, pasta, noodles, polenta, couscous, oats, quinoa and barley.
› Lean meats and poultry, fish, eggs, tofu, nuts and seeds, peas, lentils and beans.
Milk, yoghurt, cheese and their alternatives, mostly reduced fat.

You should also:

- Drink plenty of water.
- Limit intake of foods high in saturated fats.
- Limit foods with added salt and sugar.
- Limit salt to less than 4 grams of salt each day. 6 grams of salt is the maximum daily upper limit. 6 grams of salt is about a teaspoon.
- Prevent weight gain by being physically active and eating according to your energy needs.

General diet advice may not be suitable for everyone. Dietitians are a great source of individual advice to work out what is right for you.

- Getting some exercise.

Maintaining a balance between exercise and food intake helps to maintain a healthy body weight.

Aim for at least 30 minutes of moderate intensity physical activity on most (preferably all) days of the week. You don’t have to do it all in one go. It is just as effective to exercise a few times a day in 10, 15 or 20-minute sessions.

### Table 2: Lifestyle advice for the general population

<table>
<thead>
<tr>
<th>Lifestyle factor</th>
<th>Advice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>Consume a varied diet rich in vegetables, fruits, wholegrain cereals, lean meat, poultry, fish, eggs, nuts and seeds, legumes and beans and dairy products (mostly reduced fat).</td>
</tr>
<tr>
<td>Fats</td>
<td>Replace high fat foods that contain mainly saturated fats with foods that contain mainly polyunsaturated and monounsaturated fats.</td>
</tr>
<tr>
<td>Salt</td>
<td>Consume less than 4 grams of salt (equivalent to 1,600 mg sodium) each day. 6 grams of salt (equivalent to 2,300 mg of sodium) is the maximum daily upper limit.</td>
</tr>
<tr>
<td>Alcohol</td>
<td>Limit alcohol intake to two or fewer standard drinks per day.</td>
</tr>
<tr>
<td>Physical activity</td>
<td>At least 30 minutes physical activity on most or preferably every day of the week.</td>
</tr>
<tr>
<td>Weight</td>
<td>Choose amounts of nutritious foods and drinks to meet your energy needs. A healthy waist measurement should be less than 80 cm in women and less than 94 cm in men. These measurements are recommended for people from Caucasian backgrounds. If you’re from a different cultural background, speak with your doctor about your risk. A healthy Body Mass Index (BMI) for an adult is between 20 and 25. Weight loss may not be appropriate in people over 65 and should be discussed with a doctor and a dietitian.</td>
</tr>
</tbody>
</table>
This can be any form of exercise or physical activity. But the activity should increase your heart rate, make you feel warm and get you a little out of breath.

People with high blood pressure should be careful with some types of exercises. If you have high blood pressure, talk to your doctor about an exercise program.

You can still exercise even if you have weakness or difficulties with mobility since your stroke. Physical activity leads to improvements in fitness, walking speed and endurance. Talk to your doctor and/or physiotherapist about the best types of exercise for you.

**Diabetes (type 1 or type 2)**

Our bodies need a hormone called insulin to turn sugar from our food into energy. If you have type 1 diabetes, your body does not produce insulin. If you have type 2 diabetes, your body does not make enough insulin. This means your body has difficulty absorbing the sugars from food.

If diabetes is left untreated or uncontrolled it increases the risk of vascular disease (disease of the blood vessels). This is when your artery walls become hard and narrow. This increases the risk of stroke, particularly ischaemic stroke.

People with diabetes are also more likely to have hypertension. This can also increase your risk of further strokes.

If you have diabetes it is important to maintain healthy blood sugar levels to reduce your risk of having another stroke.

**Control this risk by:**

If you have diabetes it is important to keep your blood sugars within a recommended range.

If you have type 1 diabetes, it is usually recommended you check your blood sugar level four times per day, however, you may need to test more often. You will need to use insulin to keep your blood sugars in the recommended range. Insulin is usually taken by an injection.

If you have type 2 diabetes you should talk to your doctor or diabetes educator about management of your blood sugar level. You can usually use a healthy diet and regular exercise to keep your blood sugars in the recommended range.

Talk to your doctor or diabetes educator about the things you should do.

**Alcohol intake**

Drinking large amounts of alcohol increases your risk of stroke.

Regular, heavy drinking can raise blood pressure to consistently high levels. This increases the risk of both types of stroke (ischaemic and haemorrhagic).

**Control this risk by:**

You can reduce your risk of further strokes by limiting your alcohol consumption.

Your doctor may recommend you limit all alcohol consumption in the months following your stroke. After the initial recovery period it is still important to limit alcohol intake. The Australian Alcohol Guidelines recommended no more than two standard alcoholic drinks per day.
The way I view it, it’s like a painting. Before your stroke you have a self-portrait – you know what your identity is and what goals you want to reach in life. When the stroke happens, it’s like someone comes along with a paint brush and paints all over your portrait. You kind of remember what your old portrait looked like, but it’s time to paint a new one.

At the beginning you’re going to be painting big, broad strokes and these represent the first steps you take towards your recovery. As you get better, you use a different brush, a more detailed brush, until you’ve got a new self portrait. This is the ultimate goal, this is recovery. Because now you’ve got a new version of yourself, one that is probably better than the old one.

William, stroke survivor
Irregular pulse

Irregular pulse (atrial fibrillation or ‘AF’) is a type of irregular heart beat.

With a normal heart beat the blood is pumped in and out regularly with the chambers of the heart completely emptying with each beat. If the heart is beating irregularly and rapidly the blood does not move through the heart completely or smoothly.

This increases the risk of clots forming in the heart and travelling to the brain. This causes an embolic stroke.

To find out if you have AF, a doctor or nurse will check your pulse. If it feels irregular they may refer you for more tests.

Control this risk by:

Your doctor can diagnose this condition and advise you on how best to manage it. If you experience symptoms such as palpitations, weakness, faintness or breathlessness, it is important to see a doctor for diagnosis and treatment.

There are a number of treatment options for AF. These may include:

- medications to thin your blood to reduce the risk of a clot forming.
- medications or medical procedures to make your heart beat slower or more regular.

Medications

Almost everyone who has a stroke will be on medication for life. Taking your medication as prescribed will help to reduce your risk for further strokes.

Using a webster pack or dosette box may help you to remember to take your medications correctly.

Once home you can speak with your GP or pharmacist for more details about your medication. Your GP will be able to explain in clear language the changes you need to make to prevent another stroke or TIA. Your pharmacist can talk to you about different options including a medication profile and a home medication review.

Surgery

The two carotid arteries are the main arteries carrying blood to the brain. If the carotid arteries have become partially blocked, this will reduce blood flow to the brain. In this case, your doctor may advise you to have an operation called a carotid endarterectomy.

A carotid endarterectomy involves removing the plaque from the narrowed area of the artery. This improves blood flow to the brain and lowers the risk of blood clots or pieces of plaque breaking off and blocking blood flow. It is useful for people who have severe, but not total, blockage of their carotid arteries.

What else can I do to control my risk?
What are my risk factors?

Use this checklist to tick the risk factors that apply to you. Discuss this checklist with your doctor – talk about reducing your risk of another stroke.

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>Key messages</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood pressure.</td>
<td>Know your blood pressure and check it regularly.</td>
<td></td>
</tr>
<tr>
<td>Smoking.</td>
<td>Be smoke free.</td>
<td></td>
</tr>
<tr>
<td>High blood cholesterol.</td>
<td>Check your blood cholesterol level.</td>
<td></td>
</tr>
<tr>
<td>Diabetes.</td>
<td>Talk to your doctor about keeping diabetes under control.</td>
<td></td>
</tr>
<tr>
<td>Being overweight.</td>
<td>Talk to your doctor or a dietitian for help. Be active everyday.</td>
<td></td>
</tr>
<tr>
<td>Poor diet and inactivity.</td>
<td>Talk to your doctor or a dietitian for help. Be active everyday.</td>
<td></td>
</tr>
<tr>
<td>Excessive alcohol.</td>
<td>Limit your alcohol intake.</td>
<td></td>
</tr>
<tr>
<td>Atrial fibrillation (irregular heart rate or AF).</td>
<td>If you experience symptoms such as palpitations, weakness, faintness or breathlessness, see your doctor for diagnosis or treatment.</td>
<td></td>
</tr>
</tbody>
</table>
How do I know if I am having another stroke?

It’s important for you and your family and friends to know the signs of stroke so you can act quickly if necessary.

The FAST test is an easy way to remember and recognise the common signs of stroke.

Remember stroke is a medical emergency.

It is very important to seek medical assistance by calling 000. The operator will help you work out what to do next.

FAST stands for Face, Arms, Speech, Time to act fast.

The signs of stroke may occur alone or in combination and they can last a few seconds or up to 24 hours and then disappear.

Facial weakness, arm weakness and difficulty with speech are the most common symptoms or signs of stroke, but they are not the only signs. Other signs of stroke may include one, or a combination of:

- Weakness or numbness or paralysis of the face, arm or leg on either or both sides of the body
- Difficulty speaking or understanding
- Dizziness, loss of balance or an unexplained fall
- Loss of vision, sudden blurring or decreased vision in one or both eyes
- Headache, usually severe and abrupt onset or unexplained change in the pattern of headaches
- Difficulty swallowing.

If you or someone else experiences the signs of stroke, no matter how long they last, call 000 immediately. The faster you act, the more of the person you save.
Rehabilitation after stroke

Unless you are receiving palliative care you should be seen by a specialist rehabilitation team. This is to assess your suitability for ongoing rehabilitation.

The purpose of rehabilitation is to drive recovery after a stroke. Rehabilitation helps you relearn or find new ways of doing things that have been affected by your stroke.

The brain has the ability to change and adapt after a stroke. This ability is called neuroplasticity. Through changes in brain pathways, you may learn to use other parts of your brain to help you recover. Rehabilitation aims to stimulate neuroplasticity.

After your stroke, health professionals such as physiotherapists and speech pathologists will begin working with you as soon as possible. Rehabilitation can start very soon after your stroke, while you are still on an acute ward or stroke unit. Once you no longer need acute hospital care, you may be transferred to an inpatient rehabilitation unit or go home with visiting or centre-based rehabilitation.

All people benefit from rehabilitation after a stroke. To guide the decision about who will get the most out of ongoing rehabilitation, the team may consider whether you are:

- able to make enough of an improvement to make a difference to your daily life.
- able to manage the time spent in a therapy session.
- able and prepared to work with the stroke team to set and reach your goals.

You and your family or carers should be actively involved in your rehabilitation and rehabilitation choices.

The stroke team will decide, with you, if you need ongoing rehabilitation.

Each person recovers differently after a stroke. It is often difficult to predict how much recovery you will make. Some people return to 100 per cent or very close, whilst other people may continue to have impairments. The most rapid improvement usually happens in the first six months however improvements can continue for years after a stroke.

How much rehabilitation will I get?

The amount and type of therapy you get depends on your individual needs and how much you can manage. It is important to do as much practice as possible after the stroke.
It was the last thing on my mind, that I’d have a stroke. I was reasonably fit, although I did have an underlying blood condition that increased my risk of stroke. I hate to think of the trauma effect on my wife, my two girls, my friends and family, looking at me fully paralysed in the intensive care unit. I was very fortunate – that unit saved my life and the staff at rehab gave me that life back.

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

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

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

Tony, stroke survivor

Join the free online community for stroke survivors, their families and friends at enableme.org.au
Undertaking therapy tasks with family and friends throughout the day can help your recovery. Talk to your therapists about tasks you and your family can do when you are not with your therapists.

Feeling tired is common after a stroke. Making sure you are getting appropriate rest can help improve general fatigue. However, sometimes you may experience fatigue related to the stroke which may not improve with rest. Talk to your therapists about having your therapy at times when you are feeling most alert as therapy is a very important part of recovery.

Goal setting

Goal setting is a vital part of your rehabilitation and recovery. After a stroke, it is often difficult to see a path from where you are now to where you want to be. Setting goals can break things down into manageable steps to get you there.

The process starts as early as possible after your stroke and continues when you leave hospital. Goal setting is about defining what you want to achieve and making a plan to get there. It gives you and your family a target – something to aim for. Your plan can outline the steps you will take and set milestones to keep track of your progress.

There are many different ways to set goals. Talk to your stroke team about your goals and how to form realistic goals. Your stroke team may have a framework they use to help you set goals. Your goals may change as your recovery progresses.

Here are some tips to help you set goals:

- It is important that goals are specific (e.g. ‘to be able to dress myself’, rather than ‘get better’) and realistic.
- Set a timeframe to achieve your goal.
- Talk to your family and stroke team about your goals and celebrate your achievements along the way.
- Start small. Short-term goals can be stepping stones to achieve a bigger long-term goal. Your stroke team can help you to break your goals into smaller, achievable steps.

Set and keep track of your goals at enableme.org.au

After a stroke, it is often difficult to see a path from where you are now to where you want to be. Setting goals can break things down into manageable steps to get you there.
Steps to setting your goals

Try writing down your goals here. Your stroke team may have another template they use to set goals – you can keep a copy with your My Stroke Journey pack.

<table>
<thead>
<tr>
<th>Goal</th>
<th>When will you achieve this goal?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you would like help to continue to set goals once you leave hospital:
› Talk to your therapy team.
› Call us on StrokeLine **1800 STROKE** (1800 787 653)

› Log onto enableme. It will take you through steps to set a goal. You can see goals other stroke survivors have set and share your goals. enableme.org.au
The next step: planning to leave hospital

Discharge planning

This is when you and the stroke team start planning for things you may need as you leave hospital. Starting a discharge plan as early as possible is important. If needed, your stroke team will help organise services and make contact with key service providers before you leave hospital. These services may include:

› Community healthcare teams.
› Community services, e.g. home help, respite care.
› Specialist treatment appointments.
› Equipment and home modifications.

Once you are discharged, a letter should be sent to your doctor.

When you are in hospital many of the decisions made are about your health needs at that time. The advice and support of the stroke team has a lot to do with these decisions.

As you leave hospital you and your family will have more responsibility for making decisions. There is always help available.

You can:

› Talk to your doctor.
› Call the Stroke Foundation’s StrokeLine on 1800 STROKE (1800 787 653). StrokeLine has health professionals ready to help with any concerns about life after stroke.
› Visit enableme.org.au and join the online stroke community.

Where do I go after my stroke?

There are four general pathways that may occur after someone has had a stroke. They may:

1. Go directly home from the acute stroke unit or medical ward.
2. Be admitted to a specialised rehabilitation unit.
3. Go to live in an aged care home.
4. Receive palliative care.

1. Going home from the acute stroke unit or medical ward

Everyone has different needs. You and your stroke team may decide the best option is to go straight home from the acute stroke unit or medical ward. If so, the stroke team will work with you and your family to help plan your discharge.

Rehabilitation is an important part of stroke recovery and you should discuss your ongoing rehabilitation needs with the stroke team.

2. Admission to a specialised rehabilitation unit

Sometimes people are admitted to a specialised rehabilitation unit that may or may not be attached to the hospital that first treated the stroke. A rehabilitation team will work with you and your family to regain skills or learn new skills to help you continue your recovery and get on with life.
3. Aged care homes

An aged care home may be recommended after a stroke. These are for older people who have care needs that can't be met at home. Aged care homes provide 24-hour care, helping with all aspects of daily life.

Cleaning, cooking and laundry are done by staff. They are also available to help with bathing, dressing, eating and going to the toilet as needed. Nursing services are provided and GPs visit regularly. Social and recreational activities are also part of life in aged care homes.

Aged care homes are monitored, approved and funded by the Australian Government. Only an Aged Care Assessment Team (ACAT) can approve a person for an aged care home.

The stroke team will let you know if they think this is the best discharge option. A family meeting is often held to discuss the person’s care needs and why the team is recommending an aged care home. This is a chance to talk through any concerns with everyone present.

The hospital will arrange the ACAT assessment. The hospital social worker will provide advice and support throughout the process. It will be up to a family member to visit homes and to decide which ones to apply to.

For more information about residential care options ask to speak to the social worker. See the Moving to residential aged care fact sheet for more information, including a checklist to help you choose a suitable aged care home.

4. Palliative care

Palliative care is specialised care and support provided at the end of life. Palliative care includes assistance with physical, psychological, social, emotional and spiritual needs. The focus is on quality of life, providing relief from symptoms, pain and stress. Palliative care recognises how important this time is, and helps ensure family and friends can spend precious time together with their loved one.

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

Your treating team will talk to you about palliative care if needed. See the Palliative care fact sheet for more information.
Checklist for leaving hospital

You can use this checklist to help you get ready for leaving hospital.

☐ Medications
Do you have a list of medications?

☐ Follow up appointments and tests
Do you have a list of follow up appointments or medical tests?

☐ Services in your home
Has help at home been arranged for you, if needed?

☐ Equipment
Do you need any equipment before leaving hospital? Has this equipment been arranged for you?

☐ Training for your carer
Has your carer or family been given information and training to know how to help you at home?

☐ Returning to driving and work
Has anyone discussed driving restrictions with you? If you want to return to driving, or to work, do you have a plan for this?

☐ Fatigue
Has anyone discussed fatigue with you? Do you have strategies to manage fatigue?

☐ Rehabilitation options after hospital
Has anyone discussed rehabilitation options with you?

☐ Preventing another stroke
Do you have information about how to prevent future strokes? Do you know what to do if you think you’re having another stroke?

☐ Emotional wellbeing
Do you know where to get support if you need it? Are you interested in connecting with other stroke survivors via a local support group or enableme? enableme.org.au

☐ Who to contact
Do you know who you can contact if you have questions after you leave hospital?

☐ Financial support
Do you have information about government payments and entitlements?
# Appointments and services

## Appointments

Speak with your stroke team about follow up appointments organised by the hospital for you. You can write appointments in the space below. Some appointments arranged by your stroke team may be sent to you after you leave hospital.

<table>
<thead>
<tr>
<th>Appointments</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Services

Together with your stroke team, use the space below to write down services that may be useful for you and your family after hospital

<table>
<thead>
<tr>
<th>Services</th>
<th>Contact details</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>StrokeLine (Stroke Foundation)</td>
<td><strong>1800 STROKE</strong> (1800 787 653)</td>
<td></td>
</tr>
<tr>
<td>Local stroke support group</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ross was in hospital for a long time and the entire focus was on getting him well enough to come home. You always put yourself last, you put your spouse and your children first. It’s a difficult thing for carers, to find that balance. That’s been one of the benefits of the carer’s group, to talk to people who understand what you’re going through.

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

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

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

Julie, carer
Becoming a carer

Carers provide care and support for someone who needs it. Carers can be partners, family members or friends. They can be parents, children, siblings, grandparents or neighbours.

Carers help by:

› Keeping other family members and friends informed.
› Talking to the treating team and helping to make decisions.
› Helping set rehabilitation goals and joining in with therapy sessions.
› Helping with exercises and activities suggested by the treating team.

Getting ready for discharge

As a carer, you should be provided with information about the stroke, its treatment and plans for follow up care.

Before discharge home, you should receive training to ensure you can provide care safely and well. Training might include:

› Helping to get in and out of a chair or bed.
› Helping with showering, toileting or getting dressed.
› How to prevent and respond to falls.
› Helping with communication and swallowing.
› How to prepare modified food.
› Managing any behaviours of concern.

Before discharge home, it is important you are given contact details for someone you can call if you have any questions.
Carer emotions

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

It is normal for carers to feel a range of difficult emotions such as anger, resentment, frustration, guilt and sadness. There are of course positive feelings too – love and pride, along with gratitude that the person survived. It can help to talk to a trusted family member or friend. It can also help to talk to a health professional, who is outside the situation and can provide a fresh perspective.

Depression

It is very normal to feel sadness and grief in the time shortly after the stroke. These feelings should start to go away as you both get used to your new situation. However if your feelings of sadness last more than a few weeks you may have developed depression.

People with depression find it hard to function every day and may be reluctant to participate in activities they once enjoyed. If this is how you are feeling, it is very important you tell your doctor or other health professional. See the Depression fact sheet for more information.

Carer services

Carer resources and services include carer payments, respite care and counselling.

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

Respite care is short term care provided in your home or for longer periods in an aged care home. It can be planned or arranged in an emergency if needed. If you are a carer, consider planning regular respite to give yourself time to get things done and to recharge your batteries.

Counselling is also available for carers. Staff in these services understand the ups and downs of caring, and know about practical ways to make caring the best experience it can be. Commonwealth Respite and Carelink Centres can provide advice on respite and counselling services.

For details of carer services:

› See page 55.
› Call StrokeLine on 1800 STROKE (1800 787 653) for information, advice, support and referral.
› Visit enableme.org.au
StrokeLine

People call StrokeLine for many different reasons – we get people calling from their hospital bed, as well as people who are years down the track in their recovery. We hear from carers who are finding it tough, and even from friends who want to find out how they can help their mate.

The stroke journey can be a rollercoaster and we are here to help make the ride a little smoother. From navigating the health system, advocating for yourself through to setting recovery goals, our team is here to help. A big part of it is breaking the problem down: providing information on different treatment options, resources and services and working out the best option for you. You’ll come away with a plan that will work for you.

We get lots of calls about returning to driving and to work, personality changes after stroke, communication difficulties, as well as pain and fatigue after stroke. We often get calls from people with aphasia, and we are all very experienced in finding an approach to communication that works.

Call StrokeLine 1800 STROKE (1800 787 653)

› Working on StrokeLine is very rewarding. Both of my grandfathers had strokes so working in stroke is a very personal thing for me. On StrokeLine, I’m able to use over a decade of professional experience to make a real difference. Knowing that I have been able to help someone feel less alone or make their journey a little easier means so much to me.
A free online resource and community for stroke survivors, their families and supporters.

Accessibility settings
Customise your personal settings to suit your viewing – including larger text size, high contrast or aligning text to suit your vision.

Community
› Forums to ask questions and share experiences about recovery or life after stroke.
› Connect with support groups around Australia.

Ask a health professional
Ask our health professionals a question about stroke.

Goals
› Set and keep track of short, medium and long term recovery targets.
› Meet others with similar goals to share experiences and challenges.

Listen
Text read aloud for people with a vision impairment.

Resources
A wide array of fact sheets and videos, plus questions and answers on practical day-to-day life issues.

Search
Simple, Google-style search function.

Stokesaurus
A to Z guide of language used around stroke.

Tell your story
Create your own blog to tell your story.

Interested in enableme? Like to try it but need some help?
Our helpdesk is available Monday to Friday, 9am to 5pm Eastern Standard Time.
Call: 1800 STROKE (1800 787 653)
Email: strokeline@strokefoundation.org.au  enableme.org.au
The first three months after I went home were the hardest time. I lost my independence as I could no longer drive, and my husband had to become my carer as well as my taxi driver. I also found that my moods were up and down and my reactions to things felt out of proportion. I was bewildered as I’d never felt like this before my stroke.

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

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

Jenny, stroke survivor
Where to get more help after stroke

Stroke Foundation

StrokeLine:
1800 STROKE (1800 787 653)
strokefoundation.org.au

StrokeLine’s health professionals provide information and advice on stroke prevention, treatment and recovery. Our team can help you find the support and services you need. StrokeLine’s practical and confidential advice will help you manage your health better and live well.

You can call StrokeLine or visit our website to access all our resources.

Help in other languages
You can speak to StrokeLine with the help of an interpreter by calling the Telephone Interpreter Service on 13 14 50.

A stroke information sheet is also available in languages other than English. These include Arabic, Chinese, Greek, Italian, Macedonian, Turkish and Vietnamese.

Visit strokefoundation.org.au

StrokeConnections
You can receive our free StrokeConnections newsletter by calling StrokeLine on 1800 STROKE (1800 787 653).

Journey After Stroke
This is a book about stroke written for Aboriginal and Torres Strait Islander people. It was developed by the Townsville Stroke Team at Townsville Hospital, QLD.

Copies are available from:
Stroke Foundation
StrokeLine
1800 STROKE (1800 787 653)
enableme.org.au

enable me

enableme.org.au

enable me is a free online resource and community for stroke survivors, their families and supporters.

It provides:
› Resources, fact sheets and videos on a wide range of practical topics impacting daily life after stroke.
› A community forum to ask questions and share experiences with other stroke survivors, their families and carers who have ‘been there’.
› A tool to track personal goals to recovery.
› Strokesaurus – an A to Z guide to language used around stroke explained in simple words.

Get involved
You, your family or friends may wish to get involved in fighting stroke through prevention, advocacy, fundraising or volunteers programs. See strokefoundation.org.au for opportunities.

› Donate money – help us to fight stroke and support survivors.
› Donate time – become a volunteer.
› Speak up – give a voice to stroke in Australia.
› Stay informed – stay up-to-date.
› Share – help spread our message.
› Get checked and ‘know your numbers’ – check your health regularly.
Help for CARERS

Carer Gateway
1800 422 737
www.carergateway.gov.au
Carer Gateway is a new national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services.

Carers Australia
1800 242 636
www.carersaustralia.com.au
Counselling for carers. Call Carers Australia or visit their website for information on the service in your state.

Centrelink
132 717
www.humanservices.gov.au
Payments for carers.

Help with COMMUNICATION

The Australian Aphasia Association (AAA)
1800 APHASIA (274 274)
www.aphasia.org.au
Provides support and advocacy services for people with aphasia, their families and the professionals who help them.

Help from COUNSELLING

Relationships Australia
1300 364 277
www.relationships.org.au
Relationships Australia is Australia's leading provider of professional services to support relationships. It is a not-for-profit community based organisation.

Lifeline Australia
13 11 14
www.lifeline.org.au
Crisis support, suicide prevention and mental health support.

Help with DRIVING

Our ‘Driving after stroke’ fact sheet has important information on the rules about driving after stroke.

State Transport Authorities provide information regarding procedures in your state.

ACT
13 22 81
www.accesscanberra.act.gov.au

NSW
132 213
www.rms.nsw.gov.au

NT
1300 654 628
www.nt.gov.au/driving

QLD
13 23 90
www.tmr.qld.gov.au
Help from other SERVICES

My Aged Care
1800 200 422
www.myagedcare.gov.au
Information, advice and referral on aged care services.

National Disability Insurance Scheme (NDIS)
1800 800 110
www.ndis.gov.au
Information, referral and support to access services for people under 65 years.

Continence Foundation of Australia
1800 33 00 66
www.continence.org.au
Offers information and advice to people, their families, carers and health professionals in understanding and managing incontinence.

Diabetes Australia
1300 136 588
www.diabetesaustralia.com.au
A national body representing people with diabetes, health professionals and researchers.

Independent Living Centres Australia
1300 885 886
www.ilcaustralia.org.au
Provides information about products and services to help people remain independent and improve their quality of life.

Heart Foundation
Heartline: 1300 36 27 87
www.heartfoundation.org.au
Australia’s heart health charity carrying out lifesaving work in order to reduce the suffering caused by cardiovascular disease.

Help with FINANCES or RETURNING TO WORK

Centrelink
132 850 Newstart allowance
132 717 Disability and carers
136 150 Jobs, education and training
www.humanservices.gov.au
Income support and job seeking assistance.

Job Access
1800 464 800
www.jobaccess.gov.au
Information and advice about employment of people with a disability. Call to discuss eligibility.

Occupational Therapy (OT) Australia
1300 682 878
www.otaus.com.au
Provides a list of endorsed OT Driving Assessors if you require such an assessment. (See Help from other SERVICES for the contact details for individual states)
Access to allied health and rehabilitation services

For some, the rehabilitation journey will take time – months or even years. Once you return home, you may want to arrange regular access to allied health services. These services can build on the rehabilitation organised by your treatment team when you first return home.

**Your general practitioner (GP) can help.** Stroke is part of the Chronic Disease Management Plan scheme. This scheme provides Medicare rebates for up to five allied health sessions each year. Five sessions is not a lot, so make sure your allied health provider makes a plan about what you can do between sessions and after your sessions have ended for the year.

You can also ask your GP to refer you to community-based rehabilitation provided by local public hospitals. This is a good option if you have concerns about maintaining your ability to do things, or if you have new goals you want to tackle. It is particularly helpful if you need access to more than one type of allied health professional.

If you need to access counselling, you can ask your GP if you are eligible for a Mental Health Care Plan. This plan is available to you if your doctor has diagnosed you with a condition such as depression or anxiety.

This plan provides Medicare rebates for up to ten mental health sessions each year.

**Use your private health insurance if you have it.** If you have extras cover you may be able to access allied health services. If there is an allied health practice near you that offers the different types of allied health professionals you need, you’ll get the benefits of a multidisciplinary team communicating and planning together.

You can also ask your insurer whether your hospital cover will fund outpatient rehabilitation sessions. Many insurers also provide telephone health coaching, which can help you tackle risk factors and avoid having another stroke, so you can ask about that too.

**Get involved in research and check out student clinics.** Research can involve testing a therapy, so check out our website for opportunities, or call StrokeLine on 1800 787 563. Universities often offer student allied health clinics and this can be a great way to access low-cost or free allied health sessions. Again, StrokeLine can help you find the details.
Allied health professional associations

These organisations can help you find a health professional who works in stroke and who is close to you. You may be able to get a subsidy to help you pay for therapy. Speak to your GP.

**Occupational Therapy Australia**
1300 OT AUST (68 2878)
National body for the occupational therapy (OT) profession in Australia. Provides details of endorsed OT Driving Assessors if you require such an assessment.

**Speech Pathology Australia**
1300 368 835
[www.speechpathologyaustralia.org.au](http://www.speechpathologyaustralia.org.au)
The national body for the speech pathology profession in Australia.

**Australian Physiotherapy Association**
1300 306 622
[www.physiotherapy.asn.au](http://www.physiotherapy.asn.au)
National body for the physiotherapy profession in Australia.

**Dietitians Association of Australia**
02 6189 1200
[www.daa.asn.au](http://www.daa.asn.au)
National body for the dietetic and nutrition profession in Australia.

**Australian Psychological Society**
1800 333 497
[www.psychology.org.au](http://www.psychology.org.au)
National body for the psychology profession in Australia.

Stroke support groups

Stroke support groups are a good way to connect with others to exchange personal and practical advice and support.

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

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

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

**Stroke Association of Victoria**
03 9670 1117

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

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

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

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

**Aphasia Community**
[www.aphasia.community](http://www.aphasia.community)
Help for VISION

Vision Australia
1300 84 74 66
www.visionaustralia.org
Information and services for people with vision loss.

Guide Dogs Australia
1800 484 333
www.guidedogsaustralia.com
Services to help people with vision loss to increase their mobility and independence.
**Accessing information online**

The quality of information on the internet can vary.

In addition to the Stroke Foundation website strokefoundation.org.au other recommended websites include:

- Health Direct
  www.healthdirect.gov.au
- Better Health Channel
  www.betterhealth.vic.gov.au
- The Stroke Association (United Kingdom)
  www.stroke.org.uk
- The National Stroke Association (United States of America)
  www.stroke.org
- The Heart and Stroke Foundation (Canada)
  www.heartandstroke.ca
- Stroke Engine
  www.strokengine.ca

All information is correct at the time of printing.
**Stroke Foundation fact sheets**

For further information the following fact sheets are available from your stroke team or download and print for free from:

enableme.org.au

<table>
<thead>
<tr>
<th>Topic</th>
<th>Do I want to learn more about this topic?</th>
<th>Have I read this fact sheet?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged care homes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression and anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Driving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional and personality changes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incontinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility and exercise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Return to work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex and relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supporting children after a family member’s stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swallowing problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thinking and perception</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper limb management</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vision</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Aneurysm
Weak or thin spot on a blood vessel wall. The bursting of an aneurysm in a brain artery causes a haemorrhagic stroke.

Angiogram
X-ray test where dye is injected into the arteries. This provides pictures of the arteries to show up any blockages.

Aphasia
Also known as dysphasia. Impaired ability to talk, read, write or understand others when they speak.

Apraxia
Also known as dyspraxia. Impaired ability to do a body movement because the brain has difficulty planning that movement.

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

Atherosclerosis
Atherosclerosis is a type of disease. Plaques are sticky deposits that get stuck on the walls of your arteries. Your arteries get narrower and this blocks the flow of blood.

Atrial fibrillation (AF)
A heart disorder where the heart beats irregularly. Sometimes the heart may also beat too quickly.

Arteriovenous malformation (AVM)
This is a tangled mass of blood vessels. This malformation can occur anywhere in the body including the brain.

Carotid duplex
Also known as a carotid doppler. An ultrasound test that looks at the arteries in the neck that supply the brain. This is to see how well the blood flows through these arteries.

Carotid endarterectomy
An operation to unblock narrowed carotid arteries in your neck.

Cerebral angiogram
A contrast (dye) is injected into the blood vessels of the brain. This outlines them for the X-ray machine to take pictures.

Cerebral infarct
An area of brain tissue that has not received its blood supply and as a result it has been damaged. An infarct can be tiny or affect a larger part of the brain.

Cholesterol
A fatty substance present in blood. If cholesterol levels become too high the fatty substance can build up along artery walls.

Cognition
Thinking ability, including memory, thinking, language and judgment.
CT scan
CT stands for computerised tomography. X-ray imaging technique that uses a computer to produce cross-sectional images. It can be used to identify the blood vessels in the brain affected by stroke.

Dysarthria
Dysarthria is caused by weakness in the muscles used for speaking. Speech becomes slurred or a person is unable to say things clearly.

Dysphagia
Pain or difficulty swallowing.

Dysphasia
Also known as aphasia. Impaired ability to talk, read, write or understand others when they speak.

Dyspraxia
Also known as apraxia. Impaired ability to do a body movement because the brain has difficulty planning that movement.

Electrocardiogram (ECG)
A medical test that shows the pattern of electrical activity in the heart.

Embolic stroke
A stroke caused by a blood clot (an embolus) that has come from somewhere else in the body, usually the heart.

Endovascular clot retrieval
A procedure used to return blood flow to the brain. A tiny tube is inserted through an artery to the blocked blood vessel in the brain. A wire stent or suction device captures the blood clot and allows it to be pulled back out.

Enduring power of attorney
Legal agreement which enables someone with decision-making capacity to appoint a trusted person or people to make financial and property decisions on their behalf.

Family meeting
A formal meeting between the patient, their family and members of the stroke team. A family meeting is an opportunity to discuss the person’s condition, treatment and care. This is a chance to get needed information and to talk through any concerns, with everyone present.

Geriatrician
A doctor who specialises in working with older people.

Haemorrhagic stroke
Occurs when a blood vessel or an aneurysm bursts in the brain, causing bleeding inside the brain.

Hemianopia
Loss of one half of the visual field in each eye. People may experience other people appearing to have only half a face. When reading, words and sentences disappear once they fall into the missing visual field.

Hemiparesis
Weakness on one side of the body, affecting the arm, the leg or both.
Hemiplegia
Paralysis on one side of the body, affecting the arm, the leg or both.

Hemisphere
The brain is divided into two halves – a left hemisphere and a right hemisphere. The left hemisphere controls most functions on the right side of the body, while the right hemisphere controls most functions on the left side.

Hypertension
High blood pressure.

Hypertonia
Also known as spasticity. High muscle tone where the affected muscles are stiff or tight.

Hypotonia
Low muscle tone where affected muscles are floppy.

International normalised ratio (INR)
A laboratory test which measures the time it takes for blood to clot and compares it to an average.

Intracerebral haemorrhage
A type of haemorrhagic stroke caused by bleeding into the brain.

Ischaemic stroke
Stroke caused by a blood clot that blocks a blood vessel in the brain.

Lobe
The brain is made up of different areas called lobes. Each area controls a different function in the body.

Magnetic resonance imaging (MRI)
A type of scan that uses strong magnetic fields and radio waves, instead of X-rays, to take detailed pictures of the inside of the body, including the brain.

Mobility
The ability to move, for example, walking, standing up, moving from one chair to another.

Neglect
Being unaware of, or ignoring, things on one side of the body.

Neurologist
A doctor who specialises in conditions of the brain and nervous system.

Palliative care
Specialised care and support for people who are nearing the end of their lives. Palliative care can be provided in the home, a hospital, a residential aged care facility or a hospice.

Perception
The way our brain understands what it sees, feels, smells, tastes and hears.

Perseveration
Getting stuck on one idea, action or response.

Rehabilitation physician
A doctor who specialises in the rehabilitation of patients.

Rehabilitation unit
A dedicated unit which seeks to restore the skills of a person who has had an illness or
injury so as to regain maximum self-sufficiency and function. Rehabilitation units focus on the needs of each individual patient, for example, working on helping the person walk again and speak clearly again.

**Respite care**

Respite care is short term care, provided in your own home or in an aged care home. Respite is often used when a carer needs a break. It can be planned or arranged in an emergency if needed.

**rt-PA**

Recombinant tissue plasminogen activator. Also referred to as t-PA. The drug administered intravenously to break up a blood clot. See ‘thrombolysis’.

**Spasticity**

Also known as hypertonia. High muscle tone where the affected muscles are stiff or tight.

**Standard alcoholic drink**

An alcoholic drink that contains 10 grams of alcohol. This is the amount of alcohol a healthy liver can break down in an hour. Approximately equal to one pot (also known as a middy) (10 oz or 285 ml glass) of full strength beer, one glass (100 ml) of table wine or one nip (30 ml) of spirits.

**Stroke support group**

A group of stroke survivors and carers who meet regularly and provide information and support to each other.

**Stroke unit**

A set area in a hospital where a specialised stroke team look after people.

**Subarachnoid haemorrhage (SAH)**

A type of haemorrhagic stroke where there is bleeding over the surface of the brain.

**Thrombolysis**

The process where rt-PA is administered. rt-PA is a clot-busting drug that breaks down a blood clot. This allows blood flow to return to the brain.

**Thrombotic stroke**

A stroke caused by a blood clot that has formed in the brain (a thrombus).

**Transcranial Doppler (TCD)**

This is an ultrasound that measures the speed of the blood flow in the brain arteries.

**Transient ischaemic attack (TIA)**

TIA happens when the blood to your brain gets blocked for a short time. The signs are the same as a stroke, but they usually disappear in a few minutes. They don’t cause damage to the brain. A TIA can warn you that a stroke may occur.

**Verbal dyspraxia**

A type of speech problem where people have difficulty planning the movements of the mouth and tongue needed for speaking.

**Webster pack**

A webster pack is a safe and simple medication pack. It sets out all the tablets and capsules that need to be taken at each particular time of the day, for each day of the week. This makes it easy to manage medication.
The Stroke Foundation offers a range of services to assist stroke survivors, their carers and families to achieve their best possible recovery and to live well after stroke. As well as My Stroke Journey, this includes:

› StrokeLine – staffed by health professionals, this free phone service provides information and advice on stroke prevention, treatment and recovery. **1800 STROKE** (1800 787 653) Visit **strokefoundation.org.au**

› **enableme** – a free online resource and community for stroke survivors, their families and supporters. Visit **enableme.org.au**

› Follow Up – in some states, funding allows us to call stroke survivors after discharge from participating hospitals to talk about how they are managing at home and to check they have what they need to achieve their best possible stroke recovery.

› Support groups – referral to local support groups around Australia where available.
How to get more involved

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

Contact us

- StrokeLine 1800 STROKE (1800 787 653)
- strokefoundation.org.au
- /strokefoundation
- @strokefdn
- @strokefdn