

Our Family's Stroke Journey

Information for parents
about paediatric stroke



Georgia, childhood stroke survivor, with her family

About Stroke Foundation

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.



We would like to thank everyone who contributed to developing Our Family's Stroke Journey.

We would also like to thank all of our supporters for their generous contributions. Without them this publication would have not been possible.

© No part of this publication can be reproduced by any process without permission from Stroke Foundation. May 2020.

Suggested citation: Stroke Foundation.
Our Family's Stroke Journey.
Melbourne, Australia.

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

About this book

This book has information about stroke in babies, children and teenagers.

Our Family's Stroke Journey answers these questions:

- › What is a stroke?
- › How can stroke affect my child?
- › What treatment and care will my child receive?
- › What do I need to know about life after my child's stroke?
- › What help is available?

Stories from families provide insight into the road ahead. The Strokesaurus at the end of the book explains medical terms.

You don't need to read Our Family's Stroke Journey from cover to cover. Use the contents page to find the information you need when you need it. There are also pages in this book for you to write notes.

Keep this book with you in hospital, rehabilitation, doctors appointments and at home – it belongs to you.

Give people the Family and Friends brochures in this pack to help them understand your child's stroke. If you need more copies, or another copy of Our Family's Stroke Journey:

- › Print them from our website – visit strokefoundation.org.au
- › Call **StrokeLine** on **1800 787 653** and we will post them to you.

StrokeLine

StrokeLine's health professionals provide information and advice on stroke prevention, treatment and recovery.

The team can help you to find the support and services you need, whether you are a stroke survivor, parent or family member.

StrokeLine is free and provides confidential advice.

Call StrokeLine **1800 787 653**
Monday to Friday 9am to 5pm,
Eastern Standard Time.

Email StrokeLine
strokeline@strokefoundation.org.au



Zander, childhood stroke survivor, with his sister

Contents

What is a stroke?	6
Types of stroke	7
Causes of stroke	12
Risk of another stroke	13
Stroke signs	14

How can stroke affect my child?	18
Using arms and legs	19
Communicating	19
Thinking, memory and judgement	19
Personality and behaviour	19
Emotions	22
Vision and senses	22
Fatigue	22
Other effects	24
How much will my child improve?	24

What treatment and care will my child receive?	26
Tests	26
Treatment	27
Your child's treating team	28
Getting good healthcare	32
Early intervention and rehabilitation	33
Checklist	36

What do I need to know about life after my child's stroke?	40
Looking after yourself	40
Relationships and family life	41
Depression and anxiety	41
Starting or returning to childcare, kindergarten or school	42

What help is available?	46
StrokeLine	46
Little Stroke Warriors	46
For parents	46
For siblings	48
Depression and anxiety	48
Connect with others	48
Finances	49
Disability organisations	49
National Disability Insurance Agency (NDIS)	50
Therapy and rehabilitation services	51

STROKESAURUS (Medical words)	58
-------------------------------------	-----------

What is a stroke?

A stroke happens when blood cannot get to all parts of your brain.

Your brain is fed by blood vessels called arteries. Blood carries oxygen and nutrients for brain cells.

Sometimes an artery is blocked or bursts. The blood cannot get to your brain cells. If your brain cells do not get enough oxygen, they die. The part of the brain impacted is injured.

Stroke can happen at any age.

Perinatal stroke. Occurs before birth or shortly after birth, from 28 weeks of pregnancy to one month old. Other terms used are fetal, prenatal, neonatal and in utero stroke.

Childhood stroke. Occurs in a child aged from one month to eighteen years old.

Acquired brain injury and cerebral palsy

Stroke is one of several conditions that can cause acquired brain injury or cerebral palsy.

Acquired brain injury (ABI). An injury to the brain that happens at any time after birth, in children or adults.

Cerebral palsy (CP). Describes difficulty moving or controlling movement, which is caused by injury to the brain before or after birth, in babies or very young children.

About one in three children who have a stroke develop cerebral palsy



Types of stroke

Ischaemic

A stroke caused by an artery being blocked by a blood clot is called an ischaemic stroke. It's pronounced *is-key-mick*. You may also hear it called arterial ischaemic stroke (AIS). There are two places a blood clot can form:

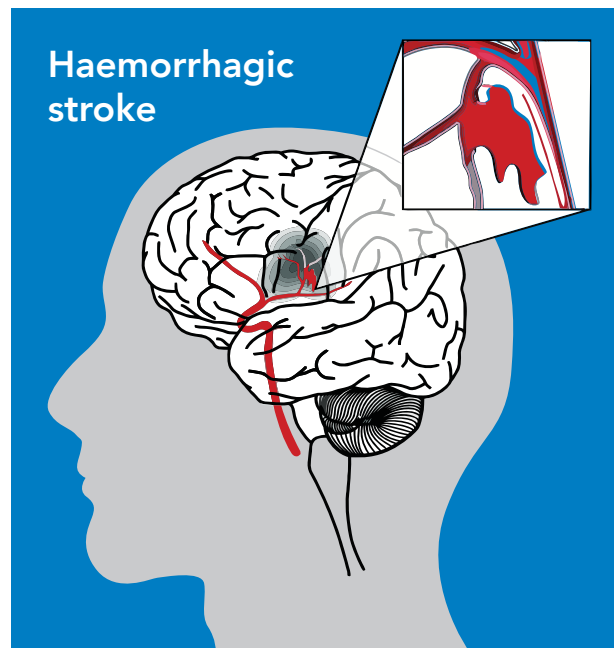
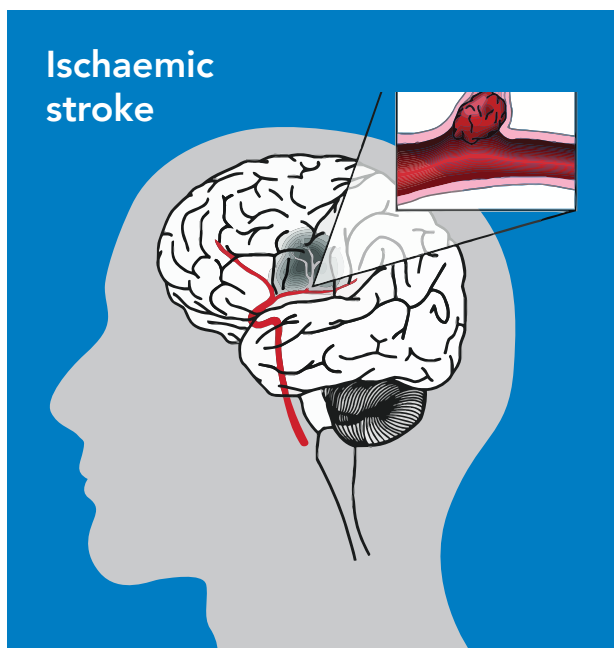
- › A blood clot can form in an artery in the brain. This is called a thrombosis.
- › A blood clot can form elsewhere in the body and travel to the brain. This is called an embolus.

The clot gets stuck in an artery too small for it to pass through, stopping the blood from getting to all parts of the brain.

Haemorrhagic

A stroke caused by bleeding if an artery breaks is called a haemorrhagic stroke. It's pronounced *hem-or-raj-ic*. Blood leaks into the brain like a bruise, injuring that area of the brain. There are two main types of haemorrhagic stroke – intracerebral and subarachnoid.

- › Intracerebral haemorrhage is bleeding within the brain itself.
- › Subarachnoid haemorrhage is bleeding under the membrane surrounding the brain.



Cerebral sinovenous thrombosis

Cerebral sinovenous thrombosis (CSVT) is a rarer type of stroke in children. CSVT causes a blood clot in the veins within the brain. This type of stroke can stop blood and fluids draining from the brain, resulting in increased pressure or bleeding.

Transient ischaemic attack (TIA)

A transient ischaemic attack is when the brain's blood supply is blocked by a blood clot temporarily. When the blood supply stops, the signs of stroke will appear.

If the blockage clears, the blood supply starts and the signs disappear. Signs may be present for a few minutes. A TIA will have no lasting impact.

The signs of stroke are on page 14.
Never ignore the signs of stroke, even if they disappear. Always call triple zero (000).

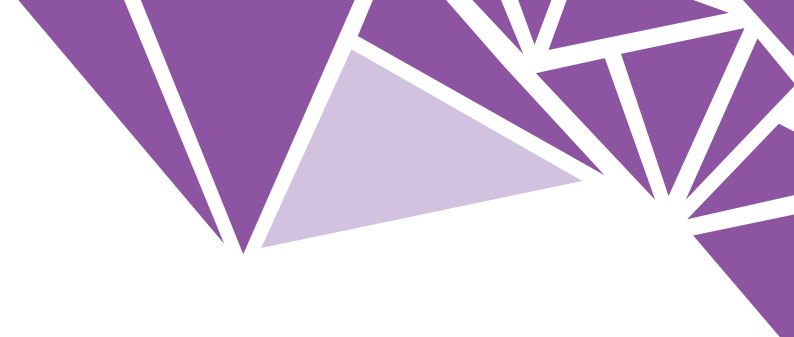


Notes

[illegible]



Anika, paediatric stroke survivor



Anika's story

My husband Kris and I were still in hospital with our newborn daughter, Anika. We were giving her a bath for the first time when she had a seizure.

Anika was rushed to the neonatal intensive care unit for urgent treatment.

That's when the medical team broke the news to us that she'd had a severe stroke.

We were shocked. My obstetrician hadn't had any concerns. All the normal tests after Anika was born had checked out fine. We had no idea something like this could happen.

But the worst thing was not knowing the pathway forwards. The medical team just didn't have any answers for us.

After four days of monitoring, Anika was able to swallow and feed, so they said we could go home. We were sick of being in hospital, but going home was pretty daunting.

What happens when we get home? What do we do?

Luckily, we got referred to the right service at just the right time, and we got Anika into early rehabilitation with a fantastic physio who helped her – and us – so much.

As hard as it is some days, I always try to find a positive thing out of every day.

Your child is going to amaze you. It doesn't matter what level they're at, they're going to amaze you.

They're incredible.

Kylie, Anika's Mum



Causes of stroke

Stroke can happen at any age.

Medical conditions can increase the risk of your child having a stroke. These are called **risk factors**. A stroke is often caused by a combination of risk factors.

It is not always possible to find the cause of a stroke in babies and children. Sometimes no risk factors are ever found.

Perinatal stroke risk factors

Risk factors for strokes before or shortly after birth include pregnancy complications, difficulties during birth and infections.

Blood clotting disorders in mother or baby make blood clots more likely to form.

Heart problems can cause blood clots to form in the heart and travel to the brain.

You did not do anything to cause your child's stroke.

Childhood stroke risk factors

Risk factors for strokes from one month to 18 years old include:

Problems with the brain's blood vessels.

In ischaemic stroke:

- › **Vasculitis.** Inflammation of the blood vessels can cause narrowing or weakness of a blood vessel. Autoimmune conditions and infections such as chickenpox can lead to vasculitis.

- › **Focal Cerebral Arteriopathy (FCA).** Can cause narrowing of blood vessels in a part of the brain.

- › **Head or neck trauma.** Trauma that causes injury to blood vessels can cause a blood clot to form or cause blood to leak from the vessel. This is known as a dissection.

- › **Moyamoya disease.** A progressive narrowing and blockage of blood vessels.

In haemorrhagic stroke:

- › **Arteriovenous malformation (AVM).** A tangled mass of blood vessels in the brain. They are usually present from birth. An AVM can cause a blood vessel to burst, causing a haemorrhagic stroke.
- › **Cavernous malformation.** A cluster of abnormal blood vessels in the brain that can leak, causing a haemorrhagic stroke.
- › **Aneurysm.** Weak or thin spot on an artery wall. Aneurysms can burst, causing a haemorrhagic stroke.

Other risk factors include:

- › **Problems with the heart or heart surgery.** The heart pumps blood to the brain, so heart problems can cause a stroke.
- › **Problems with the blood.** Clotting disorders or other disorders can make bleeding more likely.

Are strokes common in children?



Between **300** and **500** children will have a stroke each year in Australia.



Stroke is more common in newborns and young babies than older children.



Stroke affects one in 2300 to 5000 newborns.



Around a **third** of all strokes in children occur under one year of age.

Risk of another stroke

The likelihood of your child having another stroke depends on what caused it.

Some conditions may increase your child's stroke risk. Ask your doctor if there anything you can do to reduce your child's risk.

After a perinatal stroke, the risk of another stroke is very low – less than one per cent.

Any parent whose child has had a stroke worries about it happening again. Speak with your child's treating team about how you're feeling. Speaking with a social worker or psychologist can help.

Connecting with other parents can help too. Page 46 has information about Little Stroke Warriors – a group of families and survivors of paediatric stroke.

Stroke signs

If you notice any of these signs, call triple zero (000) immediately. Remember, even if you aren't sure it's a stroke, call triple zero (000).

Talk with your child's doctors about the signs you need to be aware of. Pass this information on to family, friends, childcare, kindergarten and school.

The signs of stroke in children depend on their age.



If you notice any of these signs or suspect a stroke, call triple zero (000).

Babies

- › Seizures.
- › Extreme sleepiness.

In babies, there may not be signs while the stroke is happening. You may notice changes in the way your baby develops over time, like using only one side of their body.

Toddlers, children and teenagers

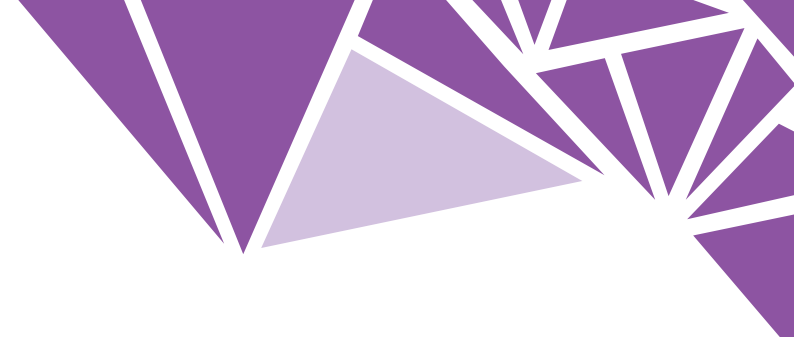
- › Weakness or numbness in the face, arm or leg, especially on one side.
- › Difficulty talking, understanding, reading or writing.
- › Trouble seeing or loss of vision.
- › Dizziness, loss of balance or poor coordination.
- › Severe or unusual headaches, nausea or vomiting.
- › Difficulty swallowing, including drooling.
- › Seizures with weakness that doesn't improve.
- › Changes in behaviour and difficulty concentrating.
- › Stroke can sometimes cause children to collapse.



Sophie, childhood stroke survivor, with her Dad



Sophie, childhood stroke survivor



Sophie's story

Sophie had a stroke when she was four.

After her stroke, we were so grateful just to have Sophie. Then in rehab we got to see her say her first word again, take her first step again. She crawled again, she walked again. All of those things we got to experience twice.

We leant on the people around us to give us strength. We realised who we could rely on.

Stroke doesn't choose what financial demographic you are, or what location you are in Australia. I just hope that, eventually, everyone can access the same resources that Sophie has been able to.

It's the beginning of a different journey. It's not a better journey, it's not a worse journey. It's just different, and we can still learn to ride bikes and climb trees.

If your kid falls and scrapes their knee, that's okay, and it's all right if they aren't what they were before the stroke.

There was this time when I was in the kitchen crying because as a mum, I was overwhelmed.

When Sophie found out why I was crying, she said to me, "How dare you. Stroke made me who I am today. I am stronger because of it."

That was three years ago, and ever since then, I've known my daughter was going to be just fine.

Amanda, Sophie's Mum

How can stroke affect my child?

Your child's brain controls everything they think, feel, say and do.

The brain has two sides: the right and left hemispheres.

- The right hemisphere controls most functions on the left side of the body.
- The left hemisphere controls most functions on the right side of the body.

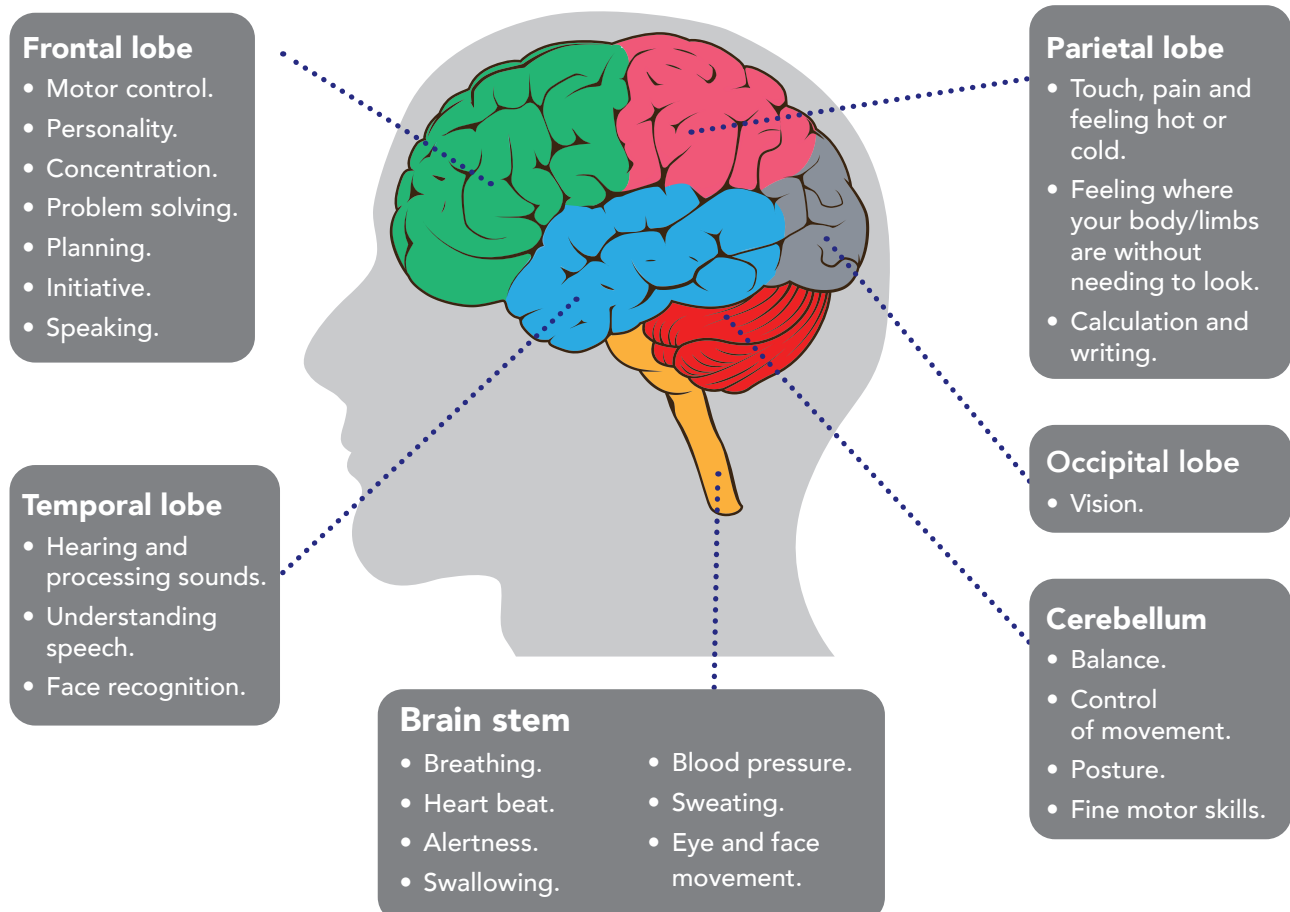
Each side of the brain is divided into areas called lobes. Each lobe controls different things.

The effects of stroke are different for every child. It depends on the area of their brain that was injured and how badly.

Effects may be minor, or they may be more serious. A child's brain is continuously developing and changing. Effects may become more obvious as your child develops. Effects can also improve over time.

Talk to your child's treating team to find out more.

Areas of the brain



Using arms and legs

Stroke can cause difficulties with sitting, standing, balancing and walking. It can also cause changes to the way the hand, arm and shoulder (upper limb) moves.

Moving, walking or using an arm may be difficult because:

- › One or both sides of their body is weak (hemiparesis).
- › One or both sides of their body doesn't move at all (hemiplegia).
- › It's difficult to plan or coordinate movement.
- › Muscles are stiff and tight. Muscles may be floppy and loose at first (hypotonia or low tone). They become stiff and tight later on (spasticity). Muscles may contract or spasm (dystonia).
- › Your child loses their balance, feels unsteady or dizzy.

Communicating

Your child may find:

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

Communication difficulties can be caused by:

- › Injury to the area of the brain controlling language (aphasia or dysphasia)
- › Weak muscles in the mouth or difficulty coordinating them (dysarthria or dysphonia).

Thinking, memory and judgement

Stroke can affect how your child thinks, remembers things and makes decisions. This is called cognition. It may be hard to:

- › Pay attention, concentrate and not get distracted.
- › Plan how to do something.
- › Do things in the right order.
- › Understand and fix a problem.
- › Process or remember new information.

Personality and behaviour

Stroke can change behaviour and personality. Your child may be:

- › Irritable.
- › Disinhibited – saying or doing things that seem inappropriate to others.
- › Impulsive – acting without thinking or doing things that are not safe or appropriate.



Isaac, childhood stroke survivor



Isaac's story

Our son Isaac had just started primary school when he had a stroke.

After his stroke, Isaac was diagnosed with global aphasia. It affected his ability to speak, to understand language, and to read or write.

I remember being in the intensive care unit. Isaac was looking at me intently. The doctors were all standing at the end of his bed saying he couldn't understand us.

But I saw this glimmer in Isaac's eye. I knew he was still there – and he was very, very frightened. It was in that moment I realised it was my role to help Isaac find his voice again. I threw myself into finding out about brain injury, aphasia and how I could help him recover.

I sought advice from other parents who had been in my situation, and the message was clear – you need to understand the brain injury. Every brain is different. Every injury is different. And don't stop therapy.

We've stayed the course with therapies including speech, music, occupational and physical therapy. Accessing neuropsychology to understand the injury and how to best support Isaac during his recovery has been invaluable.

Physical exercise and diet have been key, especially with managing fatigue. Isaac was determined to do gymnastics just 12 weeks after his surgery. He also found BMX riding helped manage his pain.

We won't stop. This comes at a cost and funding is crucial. We would encourage all families to seek support from the NDIS and the education department as early as possible.

Our son has overcome so much in such a short space of time, Isaac has been so determined. We are so proud.

Our advice to other families who are starting this journey is to take solace in knowing you are not alone. Every day is a new day. Recovery takes time.

As Isaac would say "Never give up or stop believing I can do this".

Emily, Isaac's Mum



Emotions

Your child may experience emotional changes. These may be related to the area of the brain injured, or the impact of the stroke as your child adjusts to life after stroke.

Your child may be:

- › Confused about what has happened.
- › Angry or frustrated.
- › Feeling low or anxious.
- › Worried or frightened about the future.

Your child may experience emotional lability. This is when their emotional responses don't make sense or are out of proportion for the situation. They may cry or laugh uncontrollably.

Triggers for emotional changes can include tiredness, stress, anxiety and noisy places.

Vision and senses

Stroke can affect how well your child sees. It can also affect how they sense and perceive things.

Vision. Your child may have:

- › Visual field loss – like a blind spot only bigger.
- › Blurred or double vision.
- › Problems controlling eye movement.
- › Eyes may be more sensitive to light.

Senses. Stroke can change:

- › How your child feels touch, pain, hot or cold.
- › How their body feels - numbness or pins and needles.
- › How things taste or smell.

Stroke can also change how your child's brain processes information. Their brain may not identify and filter out unneeded sensory information. This can make your child feel confused and overwhelmed, especially in busy, noisy environments. This is called sensory overload.

Perception. Your child may not:

- › Be aware of where parts of their body are or how they are moving.
- › Be aware of one side of their body. This is called neglect.

Fatigue

Fatigue is very common after stroke. Fatigue can make your child feel tired, exhausted and lacking energy.

Fatigue can affect how your child thinks. They have to work harder to do things.

It can also make the effects of your child's stroke worse. For many children, fatigue does improve with time, however it is unpredictable and can last longer than you expect.

Strategies can help manage fatigue, your child's treating team can help.



Isaac, childhood stroke survivor, with his brother

Other effects

Swallowing. Stroke can affect the muscles your child uses to move food, drink or saliva around in their mouth and how well they can swallow.

Swallowing difficulties can increase the risk of your child's airway being blocked, causing choking. Food or drink can go down the wrong way and get into their lungs, causing an infection.

Appetite. Your child may not want to eat or drink as much as they did before the stroke.

Incontinence. Your child may not know when they need to go to the toilet. They may need help to get there or be unable to get there in time.

Pain. Pain can be caused by:

- Stiff or tight muscles.
- Damage to the parts of the brain that process pain.
- Headaches.

Seizures. Recurrent seizures or fits (epilepsy) can develop. Talk to your child's doctor about what to look for and what to do if your child has a seizure.

How much will my child improve?

It is difficult to predict how much recovery will happen after a stroke, especially for a child whose brain is still developing. **Every child recovers differently and at a different rate.**

Some children recover completely, but many children will experience long-term effects. New challenges may appear as your child grows.

Talk to the treating team about your child's recovery.

Recovery is usually most rapid in the weeks to months after the stroke. However, recovery can continue for years.

Starting rehabilitation early will increase your child's chances of a good recovery.

Notes

[illegible]

What treatment and care will my child receive?

Tests

The treating team will assess your child's symptoms and do tests to confirm a stroke. Tests help find out the:

- › Type of stroke your child had.
- › Area of the brain that is injured and how badly.
- › Cause of the stroke.

The treating team will work out what tests your child needs. Some tests may be done while your child is in hospital. Others may be done when your child comes back to the hospital for appointments.

Brain scans and tests

Computerised Topography (CT) and Magnetic Resonance Imaging (MRI).

All children suspected of having a stroke should urgently have a brain scan. MRI and CT scans take pictures of your child's brain to show areas of injury and swelling. These scans confirm your child has had a stroke and the type of stroke.

A brain scan requires your child to lie very still while the machine takes a picture of their brain. Your child may be given a sedative or general anaesthetic to help them stay still.

Cerebral angiogram. A small tube called a catheter is inserted through an artery in the leg and fed into the brain. A dye is injected through the tube and X-ray images are taken. The images show how the dye moves through the arteries and veins of the brain.

This scan can see if there is a problem with the blood supply to the brain and where the problem is.

Electroencephalogram (EEG). An EEG shows the electrical activity in the brain. It may be done to find out if your child is having seizures.

Heart tests

Your child's heart pumps blood to their brain, so heart problems can cause a stroke. Heart tests include:

Echocardiogram (Echo). An Echo is an ultrasound to look at the structure and function of the heart.

Electrocardiogram (ECG). The heart's electrical activity is measured by connecting wires to stickers on your child's chest. An ECG can help determine if there is a problem with the heart rate or rhythm.

Blood tests

Blood tests are carried out to check for infection, high or low blood count, or blood clotting problems.

If an infection is suspected, your child may need a lumbar puncture. A lumbar puncture removes a sample of spinal fluid which is produced by the brain so it can be tested for infection.

Other tests

Your child will have other assessments and tests to see how the stroke affected them. Common assessments for babies may look for changes in movement, including the General Movements (GMs) assessment or the Hammersmith Infant Neurological Examination (HINE).

Common assessments for children may look for effects such as changes in thinking (cognitive tests).

Ask your child's treating team to tell you about upcoming tests and procedures, so you can work with them to prepare your child.

Treatment

Your child may receive treatment to minimise the injury to the brain and the risk of another stroke.

The type of treatment your child receives depends on:

- › The type of stroke.
- › The time passed since stroke.
- › Their age.

Your child's doctor will talk with you about treatment options for your child. They will discuss the risks and benefits with you.

Ischaemic stroke

- › **Reperfusion therapies** are early treatments to dissolve or remove the clot and return the blood supply to the brain.

- › **Thrombolysis** is when a medication is given to dissolve the clot.

- › **Endovascular thrombectomy** is the physical removal of a clot from a large artery.

These treatments are common after stroke in adults but are less commonly used in children. Research is still being done to determine how these treatments affect children and which children might benefit.

Medications to make the blood thinner and less likely to clot may be given, particularly in children with heart conditions.

Surgery may be needed to relieve the pressure caused by swelling in the brain.

Haemorrhagic stroke

Surgery may be needed to:

- › Repair the damaged artery and stop the bleeding.
- › Relieve the pressure caused by the build up of blood. This may include removing part of the skull until the swelling reduces.

Surgery may also be needed to seal or remove:

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

Your child's treating team

Many different health professionals will be involved in your child's care. Every team is organised differently and teams vary depending on whether your child is in hospital or at home. Your child's team may not have all the members listed. In some teams, people's roles may be slightly different.

You and your child are important members of the team and should be actively involved in planning and decisions about your child's care.

Doctors

Doctors manage your child's medical care.

Consultant. Specialist doctor who leads your child's medical care. In hospital, the consultant attends ward rounds and meetings at specific times.

There are different types of consultants:

- › **Neurologists** specialise in the brain, spinal cord and nerves.
- › **Neonatologists** specialise in care of newborns.
- › **Neurosurgeons** specialise in surgical management of the brain, spine and nerves.
- › **Rehabilitation specialists** focus on children's rehabilitation and recovery.
- › **Paediatricians** specialise in children's overall health and development.

Fellow. Senior doctor who is completing further specialist training such as training in paediatric neurology.

Registrar. Works with the consultant and is the senior doctor based on the hospital ward. The registrar has specialist training.

Resident. Works with the consultant and is usually the doctor you will see most often if your child is in hospital.

Intern. Has completed their medical degree and is in their first year of working in a hospital.

Nurses

Nurses observe and assess your child's health, communicate with the doctors and manage your child's daily treatment and care.

Nurse unit manager (NUM). Runs the ward in hospital, helped by associate nurse unit managers or ANUMs.

Clinical nurse consultant (CNC). Highly trained nurse in a specialist area like stroke. A stroke care coordinator may also be involved in your child's care.

Allied health

Allied health professionals and therapists manage the effects of your child's stroke, plan your child's rehabilitation and help your child make progress with their recovery.

Case manager. Helps your family with coordinating therapy and community services, and returning to activities such as school.

Dietitian. Assesses dietary needs and ensures your child receives the nutrition and fluid they require. They arrange a special diet if needed.

Neuropsychologist. Assesses and helps manage the effects of your child's stroke on their concentration, memory, judgement, mood and behaviour.

Occupational therapist (OT). Helps your child perform everyday tasks, including hand skills, play and returning to school. They provide advice on equipment to help.

Orthotist. Makes equipment to help with movement, for example an ankle splint to help support the foot while walking.

Pharmacist. Provides information on medications for your child. They give you a list of medications when you leave hospital.

Physiotherapist. Helps your child improve movement such as walking, balancing and using their arms after a stroke.

Psychologist. Looks after your child's emotional wellbeing, behaviour and mental health.

Social worker. Helps with the emotional, social and practical impacts of your child's stroke. They provide counselling and can support you in advocating for your child. They help with planning for life after hospital, particularly when you need services.

Speech pathologist. Helps your child with talking or understanding, and with reading and writing. They also help with difficulties swallowing food, drink or saliva.

Other professionals such as music therapists, play therapists or education advisors may also be involved in your child's care.



Our Treating Team

Keep a record of the health professionals supporting your family.

Name	Contact details
Consultants	
Registrar	
Resident	
Nurse unit manager	
Clinical nurse consultant	
Case Manager	



Dietitian	
Neuropsychologist	
Occupational therapist (OT)	
Orthotist	
Physiotherapist	
Pharmacist	
Psychologist	
Social worker	
Speech pathologist	



Getting good healthcare

Ask questions. Ask your child's treating team if you don't understand something or if you need more information.

Write things down. Use this book, or an exercise book, diary, tablet or phone to note:

- › Information you receive.
- › Questions you want to ask.
- › The names and contact details of health professionals you see.

Bring a friend or family member to appointments to take notes.

Ask about what's available to help.

Ask about help with parking and transport costs, and about accommodation options close to the hospital if needed. Ask if there is anything else that could help you and your family.

Talk about your concerns. If you are worried about something, speak with the health professional involved. If your child is in hospital, speak with the nurse unit manager.

You can also speak with the hospital patient advocate or consumer liaison officer.

Find them by:

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

Understand the plan for your child.

Your child's treating team will talk with you about equipment, services, therapy and follow-up.

If your child is in hospital after their stroke, the treating team will work with you to develop a plan for going home. Make sure you have a copy of the plan before you leave hospital.

Make sure you know who to contact about appointments for your child. Some services have waitlists, but after you go home, a quick phone call can reassure you that everything is in place.

Call StrokeLine. StrokeLine's health professionals provide information, advice, support and referral. Call **StrokeLine** on **1800 787 653** or email: strokeline@strokefoundation.org.au.

Early intervention and rehabilitation

Early intervention is the term most often used for services for babies and very young children.

Rehabilitation is the term used for older children.

The goal of both early intervention and rehabilitation is the same. It ensures your child has access to the therapies they need to support their development and make the best possible recovery.

We use the term rehabilitation throughout this chapter. Rehabilitation should begin as soon as possible after your child's stroke diagnosis. Rehabilitation targets all the effects of stroke.

Therapies may include physiotherapy, speech therapy, occupational therapy and psychology.

Rehabilitation will:

- › Improve the things affected by your child's stroke.
- › Help your child find new ways to do things.
- › Support your child's development at different stages, for example playing, eating, and starting or returning to childcare or school.

Therapies are tailored to your child's needs and may change as they grow and develop. The focus may be on helping babies and young children learn new skills as they develop. For older children, the focus may be on relearning skills.

The rehabilitation team will assess your child and develop a program with you, based on the treatments and therapies that will promote the best recovery.

Some children will need specialised equipment to help them move and do things.

Every activity is an opportunity for rehabilitation. Playing, brushing teeth, getting dressed, moving, eating and drinking are all part of rehabilitation. It is important you are actively involved, especially when it comes to setting rehabilitation goals. You are an important part of your child's rehabilitation team.

Rehabilitation options

Pathways to access rehabilitation may depend on the age of your child.

In hospital

If your child is in hospital after their stroke, rehabilitation should begin there. After your child's stay on the acute medical ward, rehabilitation can continue in different settings:

- › Rehabilitation unit.
- › Hospital as an outpatient.
- › At a local centre or at home.

It depends on what's best for your child, considering what's available in your area. Your child's treating team will organise continued rehabilitation after leaving hospital.

It's important you know what rehabilitation services your child has been referred to and their contact details. Ask your child's treating team if you're not sure.

At home

You need a plan for rehabilitation, even if your child did not have a hospital stay. This should start soon after diagnosis. Speak with your child's paediatrician and other health professionals involved in their care.

Rehabilitation services are organised differently across Australia. Specialist children's rehabilitation services are linked with the children's hospitals.

Your child may be eligible for therapy and support from the National Disability Insurance Scheme (NDIS). See *the information on the NDIS on page 50*.

You can also pay for therapy services from private providers. If you have private health insurance, check what is covered.

Neuroplasticity

Neuroplasticity is the brain's ability to change and adapt. It is a normal part of a child's brain development from birth and it continues throughout life. Neuroplasticity is what allows us to learn new skills.

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

Repetition is key in creating these new pathways. Your child's rehabilitation treating team can show you ways to include opportunities and practice in your daily routine.

While recovery is usually most rapid in the first few weeks and months, children can continue to improve for years after their stroke.

Getting the most out of rehabilitation

Set goals. After a stroke it can be difficult to see a path from where your child is now to where you both want to be. Talk to your child's rehabilitation team about goals – it's important you're involved in setting goals for your child's recovery.

Setting goals can help you to:

- › Focus on what's most important for your child and your family.
- › Break things down into steps, and into short and long-term goals.
- › Make a plan and follow it.
- › Track your child's progress.

Other ideas for making the most of rehabilitation include:

Keep practicing. Ask your rehabilitation team about what you and your child can do to bring therapy into the daily family routine.

Balance activity and rest. Rehabilitation is hard work. Your child will need to take breaks, get good quality rest and sleep. Practice outside of therapy time can be done in short bursts. Remember, recovery is a marathon not a sprint.

Know that plateaus are part of the process. Your child's recovery may slow down or stop for a time. Treat a plateau as a chance to reassess, not an end to recovery. Talk with your child's rehabilitation team and make a plan.

Celebrate achievements along the way. Use a diary, photos or videos to keep track of progress.

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

Checklist

Contacts

- ☐ I know who to contact if I have questions about my child's care.

Follow up tests and appointments

- ☐ I know what follow-up tests and appointments my child needs and why.
- ☐ I know how these appointments will be organised.

Services

- ☐ I know what services my family needs.
- ☐ I know how these services will be organised.

Equipment

- ☐ I know what equipment my child needs.
- ☐ I know how this equipment will be arranged.

Rehabilitation

- ☐ I know what rehabilitation my child needs.
- ☐ I know how rehabilitation will be organised and have contact details for the service.
- ☐ I know how to help my child with their recovery.
- ☐ I know whether there are any restrictions on activities or sports for my child.

Medications

- ☐ I have a list of medications for my child.
- ☐ I know why my child takes each medication and how to take them.
- ☐ I have enough medication to last until we see my child's general practitioner (GP).

Signs of stroke

- ☐ I know the signs of stroke. The signs are listed on page 14.
- ☐ I know to call triple zero (000) if my child experiences any of the signs.

Financial support

- ☐ I know what government payments and financial support are available.
- ☐ I know how to apply or who can help my family apply for financial support.

Support for you and your family

- ☐ I know who I can contact to be linked with other families affected by stroke in children.
- ☐ I know who I can contact for emotional and psychological support.

Notes

[illegible]



Georgia, childhood stroke survivor



Georgia's story

Our daughter Georgia had a stroke when she was 11 months old.

She spent the first six weeks in intensive care, and then two and a half months on the ward. We pretty much lived at the hospital the whole time.

Despite all that was happening, our main focus was to keep calm and work with the treating team, so that they could just focus on Georgia.

The key take-out for us is that you need to be a strong advocate for your child. We were there 24/7 to make sure Georgia got the care she needed. We did not want to let someone else take ownership and control.

Another thing that was really important was getting into rehab early.

We knew about neuroplasticity. We knew that if we really got onto it as soon as possible, Georgia could do amazing things.

Georgia started speech therapy, occupational therapy and physiotherapy in the hospital. Within eight weeks of leaving hospital, we had these therapies in place, along with hydrotherapy.

We found Georgia responded extremely well to intense therapy. So we did a six-week intensive, which was a lot of work for us as a family, going four days a week for six weeks. But we saw dramatic changes come from that.

The key is do not be afraid to ask questions and keep pushing for things.

Don't settle. Look for what works best for you.

Tony and Kim, Georgia's parents

What do I need to know about life after my child's stroke?

Looking after yourself

A child's stroke turns life upside down. It's normal to have mixed feelings about it. You may feel grateful your child has survived, you may also feel a sense of shock, grief or loss. You may feel unsure, alone and like nobody understands your family's situation. Feelings may change as your child's recovery journey progresses.

Everyone's journey is different, but it can be a long road with many turns. It's important to look after yourself.

It helps to:

- › Talk to a trusted family member or friend about how you are feeling.
- › Talk to the health professionals looking after your child and to your GP.
- › Use counselling services and connect with other families affected by paediatric stroke.

Talking to people about your child's stroke

Talking to people can be difficult, particularly in the early stages. What you tell people, and when, is up to you and your family.

You may need help to explain what has happened. You may need support during some conversations. Talk to your child's treating team and to trusted family members or friends.

It can help to talk about your child's strengths first and their needs second. Talk about what would help you, for example what practical or emotional support they can provide.

You can also give people the Family and Friends brochure from this pack.



Zander, childhood stroke survivor, with his Dad

Relationships and family life

Your child's stroke can bring up strong emotions that impact your relationships positively and negatively.

It can help to:

- › Talk regularly with your partner about how you're feeling.
- › Accept each other's differences. You may have different approaches to how you cope with your child's stroke.
- › Find time to spend with each other. Get help from others so you can have some time out together.

A child's stroke will affect their siblings too. The parenting skills you already have will get you through this time, but it can help to:

- › Try to find time to talk with each child and listen to their feelings.
- › Explain the stroke to your children.
- › Help them understand what is happening now and what the future may look like.
- › Let them ask questions and answer these questions honestly.
- › Ask for help so you can spend time with all your children.

Services and supports are available to help you and your family adjust after your child's stroke.

Counselling can help you sort through feelings, communicate better and develop practical strategies to improve your relationships. Talk to your child's treating team or to your doctor.

The *Supporting children after a family member's stroke* fact sheet has helpful advice. Visit strokefoundation.org.au or call **StrokeLine** on **1800 787 653**.

Depression and anxiety

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

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

You may have anxiety if anxious feelings do not go away, or if you are anxious for no particular reason.

Never ignore the signs of depression or anxiety. Speak with your doctor. Depression and anxiety are highly treatable and recovery is common. Page 48 has information on services that can help.

Starting or returning to childcare, kindergarten or school

Starting or returning to childcare, kinder or school is a major milestone in your child's recovery. There are steps you can take to help:

- › Keeping in touch with friends while your child is away from school can help your child settle back in. It can also help your child's peers to learn about the stroke.

The treating team can communicate with childcare, kinder or school to make sure your child's carers and teachers know about your child's stroke and are prepared. Your child may need some extra support to help with school work, equipment or reduced hours at school. Remember, the impact of the stroke can change over time as can the supports needed.

- › Continue to talk to your treating team, child and the school to find out what is working well and where improvements can be made.

- › Arrange a neuropsychology assessment before starting or returning to school. This can help to identify educational, emotional, social or other needs.

For children who had their stroke as a baby, a neuropsychology assessment is helpful before starting or in the first year of school. Talk with your child's treating team.



Notes

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There is a small blue tab or piece of tape visible at the top right corner. The paper appears to be part of a notebook or binder.



Emma, paediatric stroke survivor, with her Mum and Dad



Emma's story

Our daughter Emma was very delayed in rolling and crawling. When she did start to crawl, she neglected the right side of her body.

When Emma was about five months old, we were worried she wasn't reaching for things with her right hand. The family doctor told us she might just have a hand preference at an early age and not to worry about it, but we are so glad we decided to get more referrals.

Emma was ultimately diagnosed with a stroke.

We went through a merry-go-round of emotions when Emma was diagnosed, but we realised it was important to believe in Emma. Because if we didn't, she wouldn't believe in herself. Her development has been delayed but her determination is admirable.

In the past we have felt overwhelmed by all the therapy we needed to do. Emma's occupational therapist gave us some good advice: "Take some time where you're just Emma's parents, not her therapists."

So, now we are really aware that actually being her mum and dad, offering love and play time, adds to her wellbeing and her development. Probably the most amazing moments we have are when we're not doing therapy.

We think you've got to create a life as well, and not just have your child's therapy or recovery as the core focus of every day.

In the end, we're just really grateful she survived her stroke. Everything else is a bonus.

Dee & Tawhai, Emma's parents

What help is available?

StrokeLine

StrokeLine's health professionals provide information and advice on stroke prevention, treatment and recovery.

The team can help you to find the support and services you need, whether you are a stroke survivor, parent or family member.

StrokeLine is free and provides confidential advice.

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

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

On StrokeLine we take time to listen. We will tell you about the things that can help, and the resources and services available to you."

– Simone, StrokeLine occupational therapist

Call StrokeLine **1800 787 653**. We're here Monday to Friday 9am to 5pm, Eastern Standard Time.

Email StrokeLine strokeline@strokefoundation.org.au

Little Stroke Warriors

Little Stroke Warriors Australia is a group of families and survivors of paediatric stroke.

It provides families and carers with a supportive community to help steer them through the journey of stroke recovery.

Little Stroke Warriors also raise awareness of paediatric stroke throughout Australia, to make sure all paediatric stroke survivors get the treatment and care they need, and that their families are well supported.

Facebook: facebook.com/littlestrokewarriorsaustralia

Visit: <https://littlestrokewarriorsaustralia.wordpress.com>

For parents

Raising Children Network

Australian Government website with information for parents of a child with a disability. Visit raisingchildren.net.au

Carer Gateway

Parents of a child with a disability can get help from carer services. Carer Gateway is an Australian Government service providing information, support and connection to services including counselling. Call **1800 422 737** or visit carergateway.gov.au

Relationships Australia

Relationships Australia provides counselling to individuals, couples and families to support positive and respectful relationships. Call **1300 364 277** or visit relationships.org.au

"We founded Little Stroke Warriors to bring families together. We set out to be able to help just one other family. Little Stroke Warriors has grown to be more than we ever could have dreamed. Our community is unique and we are incredibly proud to be a part of it, watching these amazing warrior children beat the odds is a privilege."

Dee Banks and Kylie Facer, founders, Little Stroke Warriors



Emma, paediatric stroke survivor

For siblings

Siblings Australia

Support for siblings of children and adults with disability. Visit siblingsaustralia.org.au

Little Dreamers

Support for young people who provide care for a family member. Visit littledreamers.org.au

Young Carers Network

Information and connection for young people who provide care for a family member. Visit youngcarersnetwork.com.au

Depression and anxiety

Beyond Blue

Help with anxiety, depression and suicide prevention. They're available 24 hours a day, 7 days a week. Call [1300 22 4636](tel:1300224636) or visit beyondblue.org.au

Lifeline

Help for anyone experiencing a personal crisis with online, phone and face-to-face crisis support and suicide prevention services. They're available 24 hours a day, 7 days a week. Call [13 11 14](tel:131114) or visit lifeline.org.au

Kids Helpline

Information and support for young people aged 5 to 25. They're available 24 hours a day, 7 days a week. Call [1800 55 1800](tel:1800551800) or visit kidshelpline.com.au

Connect with others

Little Stroke Warriors Australia

Support group for families and survivors of paediatric stroke. Visit facebook.com/littlestrokewarriorsaustralia littlestrokewarriorsaustralia.wordpress.com

Stroke kids

Group for parents of kids after stroke. A place to get help, share stories and creative ideas. Visit facebook.com/strokekid

StrokeKidz

Support group for children and families affected by stroke. Visit strokekidz.org.au

Brainwave Australia

Connect, recharge and have fun through camps, events and social gatherings. Call [1300 766 819](tel:1300766819) or visit brainwave.org.au

MyTime

Free local groups for parents and family carers of children aged under 18 years with a disability, developmental delay or chronic medical condition. Visit mytime.net.au

Livewire

Online community for teenagers and their siblings experiencing serious illness, mental illness, chronic health condition or disability. Visit livewire.org.au

Heads Together for ABI

Victorian organisation which connects and supports young people and families impacted by acquired brain injury. They provide a range of social and educational programs for children, families and young adults. All programs are free. For more information, visit headstogether.org.au

Finances

Centrelink

Centrelink provides payments to help families with children, including families caring for a child with disability or a medical condition. These payments include:

- › Carer Adjustment Payment.
- › Carer Payment.
- › Carer Allowance.
- › Child Disability Assistance Payment.
- › Essential Medical Equipment Payment.

Centrelink may also be able to help with concession and health care cards. These cards may entitle you to discounts on:

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

Eligibility for help from Centrelink will depend on your family's circumstances. Call **132 717** or visit humanservices.gov.au

Carers Australia

Summary of concessions available for carers from government and businesses. Lists state government concession card schemes. carergateway.gov.au/financial-help/cards-concessions

Raising Children Network

Summary of financial support available for children with a disability. Visit raisingchildren.net.au

Brainwave Australia

Funding of essential equipment and therapy programs for children with needs beyond traditional funding criteria and limits. Call **1300 766 819** or visit brainwave.org.au

The Companion Card

Entitles eligible children and adults with lifelong disability to a free second ticket to events and activities for their companions. Visit companioncard.gov.au

Money Smart

Australian Government service providing advice on finances and debt, along with links to financial counselling services. Visit moneysmart.gov.au or call the National Debt Helpline **1300 300 630**

Disability organisations

Australian Aphasia Association

Information and resources for people with aphasia and their families. Visit aphasia.org.au

Cerebral Palsy Support Network

Information and support for people living with cerebral palsy and their families. Visit cpsn.org.au

Cerebral Palsy Alliance

Cerebral Palsy Alliance operates in New South Wales and Australian Capital Territory, providing family-centred therapies, life skills programs, and equipment for people with cerebral palsy and their families. Call **1300 888 378** or visit cerebralpalsy.org.au

Synapse

Information and services for people with a brain injury and their families. Call **1800 673 074** or visit synapse.org.au

Brain Injury Australia

Information about brain injury. Their website lists the state organisations that can provide information and support. Visit braininjuryaustralia.org.au

HeartKids

Information and support for children, teens and adults affected by congenital heart disease. Call **1800 432 785** or visit heartkids.org.au

Miracle Babies Foundation

Information and support for families of premature and sick newborns. Call **1300 622 243** (24 hours) or visit miraclebabies.org.au

Independent Living Centres

Advice, information and assessment on aids and equipment. Their website includes a dedicated section for children's products including communication, mobility, education and eating and drinking aids. Call **1300 885 886** or visit ilcaustralia.org.au

Continence Foundation of Australia

Information and advice on managing incontinence, including on the Continence Aids Payment Scheme (CAPS), which helps with some of the cost of continence products. Call **1800 330 066** or visit continence.org.au

Vision Australia

Information and services for people with vision impairment. Call **1300 84 74 66** or visit visionaustralia.org

Medic Alert

Services to ensure that your family is notified and doctors have access to your child's medical history in the event of an emergency. Call **1800 88 2222** or visit medicalert.com.au

Children and Young People with Disability Australia

Advocates to government about the needs of children and young people with disability. Their website lists organisations that can help advocate for individuals. Visit cyda.org.au

National Disability Insurance Scheme (NDIS)

The NDIS helps people with a disability get the support they need.

0–6 year olds

If your child is aged 0 – 6 years and has a **development delay or disability**, support is available through the NDIS early childhood intervention approach.

Under this approach, an NDIS Early Childhood Partner can discuss your child's needs and goals with you. You don't need assessments or reports when making contact with an NDIS Early Childhood Partner.

They can provide you with information about mainstream services. They can also provide or help you find short-term early intervention such as speech therapy or occupational therapy.

If your child needs longer-term support, your NDIS Early Childhood Partner can recommend that your child moves to an individualised NDIS plan and help you request access. If your child becomes a NDIS participant, your Early Childhood Partner will help you develop their NDIS plan. Once the plan is approved, your child will start to get NDIS funding.

7 years and older

If your child is seven years or older and has a **permanent and significant disability** affecting their ability to take part in everyday activities, support is available through an individualised NDIS plan.

Children may be eligible if a permanent and significant disability means they:

- › Usually need support from a person.
- › Use special equipment.

NDIS Planners and Local Area Coordinators can discuss your child's needs and goals with you. In an NDIS plan, funded support may include therapies, technologies or equipment to help your child with daily living activities, or modifications to your home.

To access the NDIS, you need to be an Australian citizen or have a Permanent or Special Category Visa.

More information

To find out more, start by visiting ndis.gov.au or calling **1800 800 110**

Other organisations have useful information:

Raising Children Network: raisingchildren.net.au/disability/ndis

Association for Children with a Disability: acd.org.au/information-and-resources/ndis

Yooralla: yooralla.com.au/ndis

Therapy and rehabilitation services

Your child's treating team will refer your child to rehabilitation services after their stroke. If you need to know more about your options, talk with your child's treating team or call StrokeLine on **1800 787 653**.

Children's rehabilitation services linked with children's hospitals

Specialist children's rehabilitation services are linked with children's hospitals. Many of these services also have information for families on their websites about stroke, brain injury and cerebral palsy.

New South Wales

KidsRehab at The Children's Hospital at Westmead schn.health.nsw.gov.au/find-a-service/health-medical-services/rehabilitation/chw

Rehab2Kids at Sydney Children's Hospital

schn.health.nsw.gov.au/find-a-service/health-medical-services/rehabilitation/sch

Hunter New England KidsHealth

hnekidshealth.nsw.gov.au/site/kidsrehab

South Australia

Paediatric Rehabilitation Service at the Women's and Children's Hospital wch.sa.gov.au/services/az/other/allied/paedrehab/index.html

Queensland

Queensland Paediatric Rehabilitation Service childrens.health.qld.gov.au/service-queensland-paediatric-rehabilitation

Tasmania

Paediatric Rehabilitation Service – Tasmanian Health Service outpatients.tas.gov.au/clinics/paediatric_rehabilitation_clinic

Victoria

Victorian Paediatric Rehabilitation Service vprs.org.au

Western Australia

Kids Rehab WA pch.health.wa.gov.au/Our-services/Paediatric-Rehabilitation

Medicare-subsidised sessions

You may be able to access Medicare-subsidised allied health sessions with a Chronic Disease Management Plan.

If you or your child have been diagnosed with a mental health condition, counselling sessions may be accessible with a Mental Health Care Plan.

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

Private health insurance

Talk to your provider about what is available to your child and your family.

Allied health associations

These organisations can help you find an allied health professional who works with children.

Occupational Therapy Australia

1300 68 2878 otaus.com.au

Speech Pathology Australia

1300 368 835 speechpathology.org.au

Australian Physiotherapy Association

1300 306 622 physiotherapy.asn.au

Dieticians Association of Australia

1800 812 942 daa.asn.au

Australian Psychological Society

1800 333 497 psychology.org.au

Local activities

Contact your local council or maternal and child health service to find out about activities in your area. Your child's treating team can give you advice about how these activities can be part of your child's rehabilitation.



Georgia, childhood stroke survivor and her family



Anika, paediatric stroke survivor

Notes

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There is a small portion of a yellowish-green cover visible at the top right corner. The paper appears to be part of a bound notebook or a set of loose-leaf papers.



Zander, childhood stroke survivor



Zander's story

We were having a normal Saturday morning when Zander came running in saying his head hurt.

I thought maybe he'd copped a toy to the head or something, but the tone of his voice sounded different.

I noticed his face had drooped, and I sang out to my husband to call the ambulance. I remember telling the triple zero operator I thought it was a stroke. When the ambulance arrived, they picked it as a stroke too. We were really lucky we were listened to, and Zander got the care he needed.

As Zander recovered, we really wanted to get him back to school, to start engaging with his peers again and get back into the community.

We had lots of meetings with the hospital and his physiotherapists, occupational therapist, speech pathologists, neuropsychologists, everyone. We sat down with his teachers and principal and said this is what he can and can't do. We did a PowerPoint presentation for teachers and classmates where we talked about what he's been through and how best to communicate with him.

We also meet with Zander's key people once a term and look at where he is with his education and his peers. We've found that having a communication book is a really useful tool. It goes to and from school with Zander. We can let his teacher and his aide know how he's doing each day. It gives them conversation starters that help put him at ease. They can then make notes about his day, and it saves them having to debrief with us all the time.

Make sure you read education department's policy and guidelines for students with disabilities. Ask the school to supply you the supports you need.

Juanita, Zander's Mum



Strokesaurus

Acquired brain injury (ABI)

Any type of injury to the brain that happens after birth. Stroke is one condition that can cause acquired brain injury.

Agraphia

Difficulty writing.

Alexia

Difficulty reading.

Ankle-foot orthosis (AFO)

Brace worn on the lower leg and foot to support the ankle. An AFO holds the foot to help minimise tripping and help with stability. It may also be used to hold the foot and leg in good alignment.

Aneurysm

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

Antiplatelet

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

Anticoagulant

Medication to stop blood forming clots.

Anxiety

Anxious feelings that do not go away when a stressful situation is over, or feeling anxious for no reason. Anxiety is highly treatable and recovery is common. Speak with your doctor. If you think your child is experiencing anxiety, speak with their treating team.

Aphasia

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

Aphonia

Being unable to make any sound at all.

Apraxia

Being unable to do a body movement because the brain has difficulty planning that movement.

Aspiration

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

Ataxia

Difficulty coordinating movements.

Arrhythmia

Irregular beating of the heart.

Artery

Blood vessel that carries blood away from the heart. It carries oxygenated blood to all parts of the body.

Arterial dissection

A tearing in the wall of an artery.

Arterial ischaemic stroke (AIS)

Stroke caused by an artery in the brain being blocked by a blood clot. May also be called an ischaemic stroke.

Arteriovenous malformation (AVM)

Tangled mass of blood vessels in the brain. It is usually present from birth. A blood vessel can burst in an AVM, causing a haemorrhagic stroke.

Atrial fibrillation (AF)

Irregular heart rhythm. AF can cause a blood clot to form in the heart. The clot can travel to the brain, causing a stroke.

Botulinum toxin A

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

Cardiac or cardiogenic

Relating to the heart.

Cardioembolism

Blood clot that forms in the heart and can travel to the brain. Also known as a cardiac embolism.

Cavernous malformation

Cluster of abnormal blood vessels in the brain that may leak blood, causing a haemorrhagic stroke. Also known as a cavernoma.

Cerebral angiogram

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

Cerebral palsy (CP)

Difficulty moving or controlling movement, which is caused by injury to the brain before or after birth, in babies or very young children. Stroke is one condition that can cause cerebral palsy.

Cerebral sinovenous thrombosis (CSVT)

Condition that causes a blood clot to develop in the veins within the brain. The blood clot can stop blood and fluid draining from the brain, resulting in increased pressure or bleeding.

Chickenpox

An infection caused by the varicella virus. Chickenpox can be associated with stroke.

Childhood stroke

A stroke in children from one month to 18 years old.

Cognition

Thinking ability, including memory, language and judgement.

Computerised tomography (CT)

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

Congenital

Condition that has been present since birth.

Constraint-induced movement therapy (CIMT)

Type of therapy to improve hand and arm function. The use of the stronger arm is restricted by wearing a constraint such as a mitt to encourage use of the weaker hand and arm.

Contracture

Limitation of the movement of a joint, which may be caused by muscle spasticity or weakness of muscles.

Depression

If you feel sad, down or miserable for more than two weeks, you may have depression. Depression is highly treatable and recovery is common. Speak with your doctor. If you think your child is experiencing depression, speak with their treating team.

Dissection

A partial tear in the wall of an artery. This can cause a blood clot to form at the site of the tear.



Disinhibited

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

Dysarthria

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

Dysphagia

Difficulty moving food around the mouth and swallowing.

Dysphonia

Weakness or paralysis in the muscles in and around the vocal cords, making the voice sound whispery, hoarse or rough.

Dyspraxia

Difficulty in coordinating the muscles used for speech.

Dystonia

Muscles in the body contract or spasm involuntarily. This can result in abnormal postures, pain and difficulty using the affected part of the body.

Echocardiogram (Echo)

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

Electrocardiogram (ECG)

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

Electroencephalogram (EEG)

Test that records the electrical activity in the brain. It is used to look for seizures and assess the risk of seizures.

Electrical stimulation (E-Stim)

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

Embolism or embolus

Blood clot that forms in the body and can travel to the brain. It's most common for the clot to form in the heart.

Emotional lability

Emotional responses that don't make sense or are out of proportion, or sudden swings of emotion. This may include laughing or crying uncontrollably. Also known as the pseudobulbar affect.

Endovascular Thrombectomy or Endovascular Clot Retrieval (ECR)

Physical removal of a blood clot from a large artery. A small tube called a catheter is inserted into an artery in the groin or arm and moved up into the brain arteries.

A suction device or a metal net called a stent is used to capture or remove the blood clot blocking the artery and causing a stroke.

Epilepsy

Condition causing recurrent seizures due to abnormal electrical activity in the brain. Seizures are sudden changes in body movements, consciousness or physical sensation. Stroke can be a cause of epilepsy.

Fetal stroke

A stroke before birth. Fetal stroke is a type of perinatal stroke.

Fibreoptic endoscopic evaluation (FEES)

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

Focal Cerebral Arteriopathy (FCA)

Narrowing of blood vessels in a part of the brain. Also known as transient cerebral arteriopathy.

Foot drop

Weakness or contracture causing the foot or ankle to drop down when stepping.

Full blood examination (FBE)

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

General Movements Assessment

Identifies neurological issues which may lead to cerebral palsy and other developmental disabilities. It can be completed from birth to 20 weeks of age and can identify absent or abnormal general movements.

Glucose test

Blood or finger prick test for blood sugar levels.

Haematocrit test

Test for iron levels.

Haemorrhagic stroke

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

Hammersmith Infant Neurological Examination (HINE)

The HINE is used on infants aged between 2–24 months of age to assist in the early detection of infants at risk of developing cerebral palsy.

Hemianopia

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

Hemiparesis

Weakness on one side of the body.

Hemiplegia

Paralysis on one side of the body.

Hemisphere

The sides of the brain – left or right.

High blood pressure

Blood pressure is a measure of the force with which blood presses on the walls of arteries as it is pumped around the body. High blood pressure is also known as hypertension.

Holter monitor (ECG)

Wearable device that measures your heart activity continuously over time.

Homonymous hemianopia

See hemianopia.

Hypersensitivity

Increased feeling or sensitivity.

Hypertonia

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



Hypotonia

Low muscle tone where affected muscles are floppy or loose.

Impulsive

Acting without thinking. This can cause someone to do things that are unexpected or unsafe.

Infarct

An area of the brain injured due to stroke.

Insight

Your child's understanding of the effects of the stroke and how they are impacted.

Intracerebral haemorrhage

A small blood vessel in the brain bursts causing bleeding in the brain.

Iron studies

Blood test for iron storage levels.

Ischaemic stroke

A stroke caused by an artery in the brain being blocked by a blood clot or narrowing.

Judgement

The ability to make good decisions.

Leukocyte test

Test that shows white blood cell count.

Lobes

Different areas of the brain.

Magnetic resonance imaging (MRI)

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

Mobility

Moving, walking and standing.

Moyamoya

Rare condition that causes progressive narrowing or blockage of the main blood vessels in the brain. This can affect blood flow to the brain.

Muscle spasticity

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

Nasogastric tube (NG tube or NGT)

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

Neglect

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

Neonatal stroke

A stroke that happens from birth to one month of age. Neonatal stroke is a type of perinatal stroke.

Neuropathic pain

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

Neuroplasticity

The brain's ability to change. After a stroke, pathways in the brain can change so that uninjured parts of the brain can take over the jobs of injured areas. Practice and repetition of tasks is vital to promote neuroplasticity.

Nystagmus

Constant, unsteady or jerking movement of the eyes.

Oedema

Swelling due to fluid build up.

Orientation

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

Orthotic

Brace or splint fitted to any part of the body to help support or improve alignment.

Percutaneous endoscopic gastrostomy (PEG) feeding

A tube is surgically inserted into the stomach through the skin. Used when someone cannot safely eat or drink through their mouth over a prolonged period of time.

Perception

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

Perinatal stroke

A stroke before birth or shortly after birth. Perinatal stroke includes stroke from 28 weeks of pregnancy to one month old.

Perseveration

Getting stuck on one idea, action or response.

Plasticity

See Neuroplasticity.

Quadrantopia

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

Recognition

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

Risk factor

Factors that increase the chances of a stroke happening, such as certain medical conditions.

Seizure

Sudden changes in body movements, consciousness or physical sensation. A seizure is caused by abnormal electrical activity in the brain.

Sensory overload

Difficulty identifying and filtering out unnecessary sensory information can make some situations overwhelming such as busy, noisy environments.

Short-term memory

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

Shoulder subluxation

Changes in the muscle such as weakness or spasticity that can cause the upper arm bone to sit lower in the shoulder socket. A subluxed shoulder can become painful.

Sickle cell disease (SCD)

Blood disease that causes red blood cells to get stuck in arteries. Sickle cell disease is a risk factor for stroke.

Spasticity

See Muscle Spasticity.

Strabismus

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



Subarachnoid haemorrhage (SAH)

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

Thrombolysis

A drug is given to dissolve a clot in an artery in the brain that is causing a stroke.

Thrombosis

A blood clot that forms in an artery.

Transcranial doppler (TCD)

A test using ultrasound to measure the speed of blood flow in the brain arteries.

Transient ischaemic attack (TIA)

The blood supply to the brain is blocked temporarily. If the blockage clears, the blood supply starts again and the signs of stroke disappear. A TIA will have no lasting impact, making it different to a stroke. A TIA is a warning sign that a stroke may happen. The signs of stroke are on page 14. Never ignore the signs of stroke, even if they disappear. Always call triple zero (000).

Transoesophageal echocardiogram (TOE)

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

Vasculitis

Inflammation of the blood vessels.

Vein

Blood vessel that carries blood from other parts of the body back to the heart.

Verbal Dyspraxia

See Dyspraxia.

Videofluoroscopy

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

Visual agnosia

Difficulty recognising familiar faces and objects.

Visual field loss

The visual field is the entire area that can be seen when your eye is directed forward. Stroke can cause loss of vision in part of the visual field.



Hailey, childhood stroke survivor, and her Mum



Hailey, childhood stroke survivor



Hailey's story

I was six when I had my stroke, and I'm 27 now. It was a confusing and scary time.

I was experiencing things and feelings I couldn't put into words.

At first I didn't understand what had happened to me. At six, I didn't know what my brain did or even what a stroke was.

For a time, I was quite ashamed of what had happened, and I became frustrated and annoyed with myself.

Thankfully, I found out about Heads Together, an organisation in my state that provides camps for kids with acquired brain injury and their families.

It's a really good place just to be yourself and not have to deal with the level of stigma that's out there in the wider community.

You also get to have that sounding board and an advice network.

Now, I've got a partner and a step-son, and I work as a part-time carer for young people with mental health issues and acquired brain injury in a residential setting.

I also volunteer for Heads Together to give something back, because I don't want anyone else to feel as isolated as I did.

Overall, it's just a matter of learning to accept that these are the cards that you've been dealt, and you've got to figure a way around the issues you face, and through time that's what I did.

I can do everything anyone else can do, but for me, I have a different way of going about it.

Hailey



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**