



strokefoundation

Childhood stroke



This booklet has been a joint production between the National Stroke Foundation, Royal Children's Hospital Melbourne and Strokidz.

National Stroke Foundation

The National Stroke Foundation is a national not-for-profit organisation working across the stroke journey supporting stroke survivors, carers, health professionals, governments and the public to reduce the impact of stroke on the Australian community. We are the voice of stroke in Australia. Our mission is to stop stroke, save lives and end suffering.

We will achieve this by:

- Raising awareness of the risk factors and signs of stroke and promoting healthy lifestyles.
- Improving treatment for stroke to save lives and reduce disability.
- Improving life after stroke for stroke survivors.
- Encouraging and facilitating stroke research.
- Advocating for improved stroke prevention, treatment and support.
- Raising funds from the community, corporate sector and government to continue our mission.

Photography: © Bronwyn Terry Photography

Strokidz

Strokidz, a group located in Melbourne, Australia, was formed to provide support for children and families affected by stroke.

We offer peer support on a personal, informative and social level.

Being parents of children who have suffered a stroke we are well aware of the wide ranging effects and medical conditions these children inherit, along with the emotional roller coaster parents take in obtaining information about their child's diagnosis.

We exist to gather information and share experiences with interested families. We provide a network of contacts to services provided by government and private agencies. Social functions are organised to help families meet and share experiences.



Contents

Stroke

What is a stroke?	4
What is a TIA?	4
How will I know if my child is having a stroke or TIA?	5
How often do children have strokes?	6
What causes stroke in children?	6

Stroke assessment

What tests will be done?	7
What medical treatment should my child receive?	8
Will my child have another stroke?	8

Stroke recovery

What are the effects of stroke?	10
Will my child recover from the stroke?	11
Who will help my child recover?	11

Leaving hospital

Discharge planning	13
Strokidz (support group)	13

Personal stories

Adam	14
Callum	15
Alex	15

More information

Children's hospitals	17
Health professional associations	18

Commonly used words

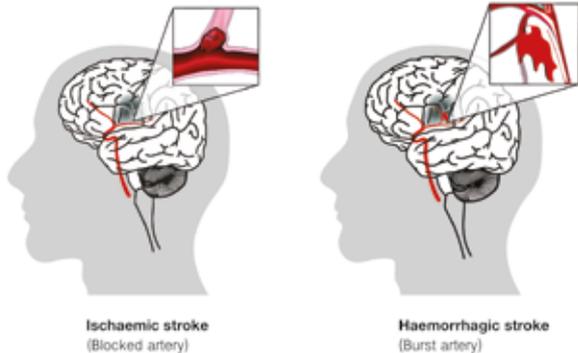
19



What is a stroke?

A stroke happens when the blood going to the brain through the arteries is suddenly disrupted or stopped. Blood may stop moving through an artery for two reasons:

- The artery breaks or bursts causing bleeding. This is called a haemorrhagic stroke and accounts for half of childhood stroke.
- Blood flow is blocked by a blood clot. This is called an ischaemic stroke and accounts for the other half of childhood stroke.



When blood stops flowing, the brain does not receive the oxygen it needs, and therefore brain cells in the area die and permanent damage can occur.

What is a TIA?

TIA stands for transient ischaemic attack or a 'mini-stroke'. The risk factors and symptoms of a TIA are the same as those for a stroke but the symptoms go away within 24 hours.

Someone who has a TIA has a much greater chance of having a stroke. TIA should not be ignored. Seek immediate medical attention if your child shows the symptoms of a stroke or TIA.

TIA stands for transient ischaemic attack or a 'mini-stroke'. The risk factors and symptoms of a TIA are the same as those for a stroke but the symptoms go away within 24 hours.



How will I know if my child is having a stroke or TIA?

This depends on your child's age and stage of development. Strokes that occur in **babies** often show themselves as seizures, but they can be missed until parents notice later that the baby has difficulty moving a part of their body. Sometimes strokes may affect the way a baby is developing.

Toddlers or **older** children may develop sudden signs such as:

- Weakness in an arm or leg, especially on one side. This can cause difficulty with walking, standing or using the affected arm. For older children this may also include numbness in the arm or leg.
- Difficulty talking, understanding, reading, writing or concentrating.
- Trouble seeing in one or both eyes.
- Dizziness, loss of balance or poor coordination.
- Difficulty swallowing including drooling.
- Severe or unusual headaches, nausea or vomiting.
- Occasionally strokes can cause children to collapse, to change behaviour or to have a seizure.

If you notice any of these signs **seek immediate medical attention.**

How often do children have strokes?

The exact rate is unknown but every year approximately three to thirteen children in every 100,000 will have a stroke. Strokes can occur in all age groups – from newborns to older teenagers. Sometimes strokes occur in babies before they are born with an estimate of one newborn in every 2,300 – 5,000 having a stroke.

What causes stroke in children?

The causes of childhood stroke are poorly understood with little published research.

All strokes, regardless of age, are a result of disruption of blood going to or from the brain resulting in brain cells in the area dying and permanent damage potentially occurring.

The reason for this disruption may be different for children and adults.

A number of medical conditions can increase the chance of your child having a stroke. These include:

- Some types of heart disease or heart surgery.
- Abnormal or inflamed blood vessels in the brain.
- Blood clotting problems.
- Low blood count.

- Central venous catheters.
- Some types of cancer.
- Recent major infections around the ear sinuses or nose
- Some viral infections (for example research has shown that chickenpox may cause ischaemic stroke in children).
- Head injury.
- Dehydration.
- Prolonged low blood pressure.
- Brain tumours.
- Other conditions such as sickle cell disease and thalassaemia.

About a quarter of all children who have had a stroke do not have any of these risk factors. It is unknown why these children have strokes.

The cause of stroke in newborns is usually unknown. Risk factors include pregnancy complications, difficulties at birth, blood clotting disorders and heart problems.

Discuss with your doctor your child's risk factors and the potential causes of the stroke.

Stroke assessment

What tests will be done?

Early testing will help identify if your child has had a stroke and what type of stroke he or she has had. This will guide your child's treatment. The tests organised by your doctor will be different for every child. Ask your doctor what types of tests are being done and why.

Common tests include:

Brain scan: A **CT scan** (computed axial tomography) or **MRI** (magnetic resonance imaging) are scans or images which tell where your child's stroke has occurred in the brain and what type of stroke it was. All children suspected of having a stroke should have a brain scan in the first 24 hours after the stroke. Brain scans require the ability to lie very still, so babies and young children may need to be asleep during the tests.

Children may need to have anaesthesia (medicine to sleep) during the scan.

Angiograms: This identifies if any arteries in the brain are blocked. A small amount of dye is injected into the blood vessels supplying the brain and an x-ray is used to watch the dye move through the brain's arteries.



Ultrasounds: Can be used in babies to get pictures of the brain from the soft spot on top of the skull. All babies have these soft spots (fontanelles). These pictures are not very detailed and other tests are almost always needed if an ultrasound test shows a baby has had a stroke.

Echocardiogram: This is an ultrasound which looks at the structure of the heart. It is done to check whether a clot travelling from the heart to the brain has caused the stroke. The scanning, which is painless, is usually done by placing a small instrument on the child's chest.

Blood tests: Look at your child's clotting system, blood count, and immune system to see if your child has had any recent infections.

Other: Your child's temperature, blood pressure and levels of oxygen in the blood will also be monitored. Your child should also receive assessments from a variety of health professionals listed on page 18.

What medical treatment should my child receive?

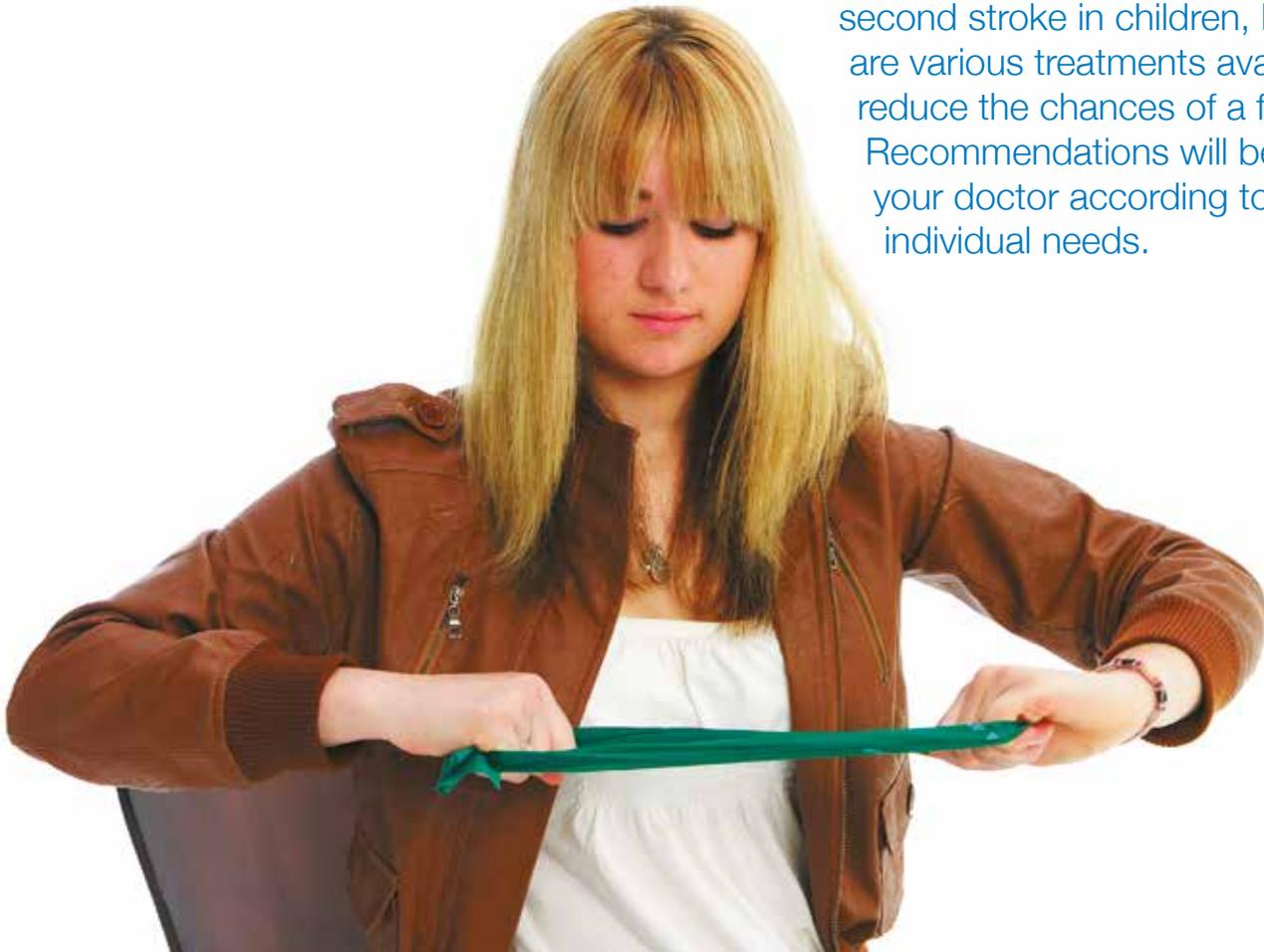
This will depend on the factors that caused your child's stroke. Drugs that make the blood thinner and less likely to clot (such as aspirin, Heparin, Clexane or Warfarin) may be considered for children who have had an ischaemic stroke.

Some children with haemorrhagic strokes, but not all, may require surgery to the brain if they have reduced consciousness (for example, if they are not awake or alert) or if the blood is building up and causing pressure in their brain. Your doctor will discuss the need for surgery, risks and benefits and if surgery is recommended.

Will my child have another stroke?

This will depend on the underlying cause of your child's stroke and type of stroke. Research indicates somewhere between 20 to 40 percent of children have recurrent strokes. Little is known about the prevention of a second stroke in children; however there are various treatments available to try to reduce the chances of a further stroke. Recommendations will be made by your doctor according to your child's individual needs.

Little is known about the prevention of a second stroke in children, however there are various treatments available to try to reduce the chances of a further stroke. Recommendations will be made by your doctor according to your child's individual needs.



Stroke recovery

What are the effects of stroke?

The effects of stroke are different for every child and depend on where in the brain the stroke happens, the size of the stroke, your child's general health and how quickly you were able to get medical treatment. After a stroke, your child may experience difficulties or changes with the following:

Walking, crawling, standing or running: Due to weakness (hemiparesis) or paralysis (hemiplegia) on one side. The movement of both sides of the body may be affected if the stroke has involved both sides of the brain.

Using an arm: This can affect drawing and writing skills and the ability to do everyday things like getting dressed and self-feeding.

Balancing or coordinating movements: Difficulty standing or sitting without falling or leaning to one side.

Communicating: Difficulty talking, understanding what people are saying, reading or writing.

Thinking: Difficulty with thinking skills, memory and difficulty concentrating and paying attention.

Swallowing: Difficulty swallowing different foods, drinks or even saliva resulting in drooling.

Vision: Difficulty seeing the things to one side or perceiving how close objects are.

Ignoring one side of the body: Difficulty looking towards or acknowledging the weaker side of the body.

Sensation: Difficulty receiving messages from the five senses (smell, touch, taste, sight, and hearing).

Toileting: Difficulty controlling bladder and bowel movements.

Emotions: Feelings of anger, frustration or being upset. Sudden changes in mood can also be common.

Fatigue: Feeling of exhaustion, weariness or feeling too tired to do something or finish an activity.

Appetite: Not wanting to eat or drink as much as before.



Will my child recover from the stroke?

Your child's recovery will depend on the type of stroke, the part of the brain affected, how old your child is, and any other medical conditions your child has.

Some children recover completely but other children may be left with long-term difficulties including seizures, physical disability, speech or learning difficulties. It is often difficult to predict how well your child will recover.

Early rehabilitation will increase your child's chances of a good recovery. Rehabilitation needs are different for everyone. Rehabilitation can happen within the hospital you are being treated at, at another hospital, at a community health centre or at home.

Who will help my child recover?

A number of health professionals are responsible for assessment, daily care, treatment and the provision of education and support to you and your child. It is important that you are actively involved in your child's care to set appropriate goals and to help with the various sorts of therapy and rehabilitation.

Dietitian: Ensures your child receives the nutrition and fluid they require.

Doctor: Coordinates your child's medical care and assists you to make informed choices.

Education advisor: Helps support the child and school staff with advice in preparing for return to kindergarten or school.

Haematologist: A specialist doctor in the care of disorders related to blood and circulation, including blood flow to the brain.

Neurologist: A specialist doctor in the care of disorders related to the nervous system including brain function.

Nurse: Provides 24 hour a day care.

Occupational therapist: Helps your child perform everyday tasks, including play and returning to school. This may include advice on equipment that can help.

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

Paediatrician: A specialist doctor in the care of babies, infants and children. Coordinates your child's medical care and assists you to make informed choices.



Physiotherapist: Helps your child improve movement such as walking and balancing after stroke.

Psychologist: Helps assess your child's thinking skills.

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

Social worker: Helps with the emotional and social results of your child's stroke and organises community resources.

Your child may need to continue seeing some health professionals once he or she has returned home. Your medical team will organise for you to continue therapy in the community.

If your child is a baby or pre-schooler when diagnosed with stroke, they may be referred to an Early Intervention Service for therapy after hospital.

If your child is school-age it may be advised that returning to school occur gradually with some careful planning. Keeping in touch with school friends during the recovery period can assist your child to settle back into school. Your health professionals and an educational advisor may assist in supporting your child's return to school.

Leaving hospital

Discharge planning

Before you leave the hospital, your health care team will talk with you as a family. Together you will talk about your child's support, educational, ongoing therapy and follow-up assessment needs. They will also link you into community services and discuss any equipment you may need to help your child at home. Together you will develop a plan for going home. Ask as many questions as you need during this meeting.

Strokidz

Parents and carers often report feelings of helplessness, distress and guilt from watching their child's pain and fear, and being unable to help them. They worry about what will happen when they go home.

Sometimes the greatest comfort can be found talking to other parents who understand what you are going through. Stroke affects each child differently but the emotional and physical experience may be similar. Other parents can talk about what helped them and their child recover, and how and where to access services in the community.

Strokidz is a childhood stroke support network formed by, and for, parents of children who have had a stroke. The Strokidz network is there to support you and your family.

For more information about the group visit:
www.strokidz.org.au



Personal stories

Adam

Adam suffered a stroke while in the womb. Despite a seemingly normal and healthy pregnancy, mum Sally-Anne said she knew something was seriously wrong soon after her son was born. His right arm was covered in ulcers and was floppy. He showed little interest in his surrounds and his head was always turned towards his left shoulder. Sally-Anne said a pediatrician dismissed her concerns. It was not until Adam was seen by specialists at the hospital at three months old that her fears were confirmed.

“It was pretty devastating,” Sally-Anne said. “We were told he might never walk or talk.” Adam has defied the grim prognosis, starting to walk at the age of two and talk at three.

He loves his food, playing with puzzles, enjoys kinder and playing with dad Darren, brothers Luke, 13, Mitchell, 6, and sister Emma, 3. “He is a typical four-year-old monster,” his proud mum laughs. But the stroke has left its mark. Adam’s right arm is growing more slowly than his left, and its use is limited. He also developed epilepsy and has learning difficulties.



Callum

Callum was a happy active child who had occasional asthma. One morning he was not his usual energetic self. He seemed distracted, uncooperative, lethargic and uncoordinated. His mum, Rebecca noticed that his face wasn't right, and took him to the emergency department where after an initial consultation he had an MRI. This is when it was found Callum had suffered a stroke. He was immediately placed on a Heparin drip and admitted to a ward.

Callum has been fortunate, says Rebecca, he only stayed in hospital for a week. He continues to take his daily aspirin, and has his regular check ups. Rebecca says to the unaware, Callum looks 'normal' as there appears to be no lingering issues however, he still gets weakness and fatigue, his speech has been affected (but is improving rapidly), as have his fine motor skills and he has some social developmental delays. His outlook is good and he is currently attending mainstream school.

Alex

Alex had a stroke at school when she was in Year 5. She was playing sport when she lost vision in her right eye and started to feel dizzy. She asked some of her friends to get their teacher, as she wasn't feeling right. Her teacher noticed she

was dragging her right leg as she was walking towards her. She was helped into the Principal's office where they noticed that Alex couldn't communicate with them and had no control of her right side. An ambulance was called and she was taken to hospital.



Her mum, Susi, was called at work and says “I hope I will never receive a call like that again.”

Susi and Rob (Alex’s dad) raced to the hospital to meet the ambulance. As soon as Susi saw Alex being wheeled out of the ambulance she says that she knew that something major had happened as she did not look like the girl that she had sent off to school that morning.

After numerous tests, a CT scan and an MRI it was suspected that Alex had a stroke but more tests were needed to confirm. “To see Alex lying there not being able to communicate or move was surreal and we were hoping that it was just a nightmare,” Susi says.

The next day it was Alex’s birthday, she was turning 11. She still couldn’t move or talk and it took three weeks before some feeling came back into her arms and legs and the difficult process of learning to do everything again started. Eight weeks later she walked out of hospital and started to slowly get back to a normal life. She started going back to school for half a day per week, and then one day, and then two and so on.

A few months later, Alex had a TIA which put her back in hospital for 10 days, and then another one three months after that, requiring another 10 day stay. Luckily since then there has been nothing. She has now started High School and is doing extremely well. Susi says “Alex is an inspiration to us all with her strength, courage and determination to live the life that she has planned for herself.”



More information

The following sites may be helpful in finding information on medical and rehabilitation services in your area. If you can't find the information you need, contact your local community health centre, children's hospital or local government office.

Contact the National Stroke Foundation or Strokidz for details of other useful organisations or for more written information.

National Stroke Foundation

www.strokefoundation.com.au

Call StrokeLine: 1800 STROKE (1800 787 653)

Strokidz (Childhood Stroke Family Support Group, Australia)

www.strokidz.org.au

Andrew 03 9885 4477

International Alliance for Pediatric Stroke

www.iapediatricstroke.org

Children's hospitals

New South Wales and Australian Capital Territory

The Children's Hospital at Westmead

www.chw.edu.au/rehab/brain_injury

Sydney Children's Hospital, Randwick

www.sch.edu.au

Queensland

Queensland Paediatric Rehabilitation Service at the Royal Children's Hospital, Brisbane

www.health.qld.gov.au/rch

Victoria

The Royal Children's Hospital, Melbourne

www.rch.org.au

www.rch.org.au/rehab/index.cfm?doc_id=9485

Victorian Paediatric Rehabilitation Service by region

www.health.vic.gov.au/vprs/contacts.htm

South Australia

The Women's & Children's Hospital, Adelaide

www.wch.sa.gov.au

Novita Children's Services

www.novita.org.au

Northern Territory

Northern Territory Government – Children, Youth and Families

www.health.nt.gov.au/Child_and_Youth_Health/index.aspx

Western Australia

Princess Margaret Hospital, Perth

www.pmh.health.wa.gov.au/services/paediatric_rehabilitation

Tasmania

Department of Health and Human Services –
Disability Services

www.dhhs.tas.gov.au/service_information/disability/disability_services

Headway Support Services

www.headwaytas.net.au

Health professional associations

To find a health professional in your local area contact the relevant organisation.

Speech Pathology Australia

www.speechpathologyaustralia.org.au

Occupational Therapy Australia

www.otaus.com.au

Australian Physiotherapy Association

www.physiotherapy.asn.au

Australian Association of Social Workers

www.aasw.asn.au

Australian Psychological Society Ltd

www.psychology.org.au



Commonly used words

Anaemia: Not enough red blood cells that carry oxygen around the body.

Aphasia: Difficulty communicating making it hard to talk, understand other people talking, read and/or write.

Apraxia: Difficulty with moving body parts due to impaired planning and sequencing of movement that is not due to muscle weakness.

Ataxia: Difficulty coordinating body parts to move together resulting in trouble walking and balancing.

Arrhythmia: Irregular beating of the heart.

Cardiac/cardiogenic: A condition of the heart.

Congenital: A condition that has been present since birth.

Dysarthria: Difficulty producing clear speech due to weak or damaged speech muscles.

Dysphagia: Difficulty eating, drinking, swallowing. This

occasionally involves drooling.

Dysphasia: Difficulty communicating making it hard to talk, understand other people talking, read and/or write.

Dyspraxia of speech: Difficulty producing clear speech sounds due to impaired planning and sequencing of movement that is not due to muscle weakness.

Emboli/embolism: A small object from the body such as a blood clot or plaque that travels through the blood vessels and can block the blood flow to a part of the brain.

Haemorrhage: The flow of blood or bleeding from a hole in a blood vessel.

Hemiplegia: Inability to deliberately move a body part affecting only one side of the body. There is usually no movement in the body part when trying.

Hemiparesis: Difficulty in deliberately moving a body part

affecting only one side of the body. There is usually some movement of the body part when trying.

Homonymous hemianopia: Problems seeing things on one side of your body e.g. because neither eye can see things on the left or right hand side of the body.

Intracerebral haemorrhage: A blood vessel in the brain breaks or bursts causing bleeding.

Ischaemia: Blood flow is blocked to a part of the body by a blockage e.g. a blood clot in the blood vessel or swollen blood vessel.

Nasogastric (NG) tube feeding: A method of feeding via a tube that is inserted in the nose and then goes into the stomach. Used when a child cannot safely eat or drink by mouth.

Neglect: Difficulty looking, responding to, or moving towards one side of the body.

Percutaneous endoscopic gastrostomy (PEG) feeding: A method of feeding via a tube that is surgically inserted into the stomach through the skin. Used when a child cannot safely eat or drink through their mouth over a prolonged period of time.

Seizure: Sudden involuntary movements of the body and lack of awareness (consciousness) of what is happening. A seizure is caused by abnormal electrical activity in the brain.

Subarachnoid haemorrhage: A blood vessel in the space between the brain and the skull breaks or bursts causing bleeding.

Thrombus: A small object from the body such as a blood clot or plaque that forms in the blood vessel and can block the flow of blood.

Vascular: Refers to the blood vessels.



strokefoundation

www.strokefoundation.com.au

Call StrokeLine **1800 STROKE** (1800 787 653)

ISBN 978-0-9805933-2-7

© National Stroke Foundation, December 2009.

No part of this publication can be reproduced without permission from the National Stroke Foundation, Strokidz or Royal Children's Hospital Melbourne.

Reprint April 2014