

A Family Guide to Pediatric Stroke

HEART AND STROKE FOUNDATION

2014



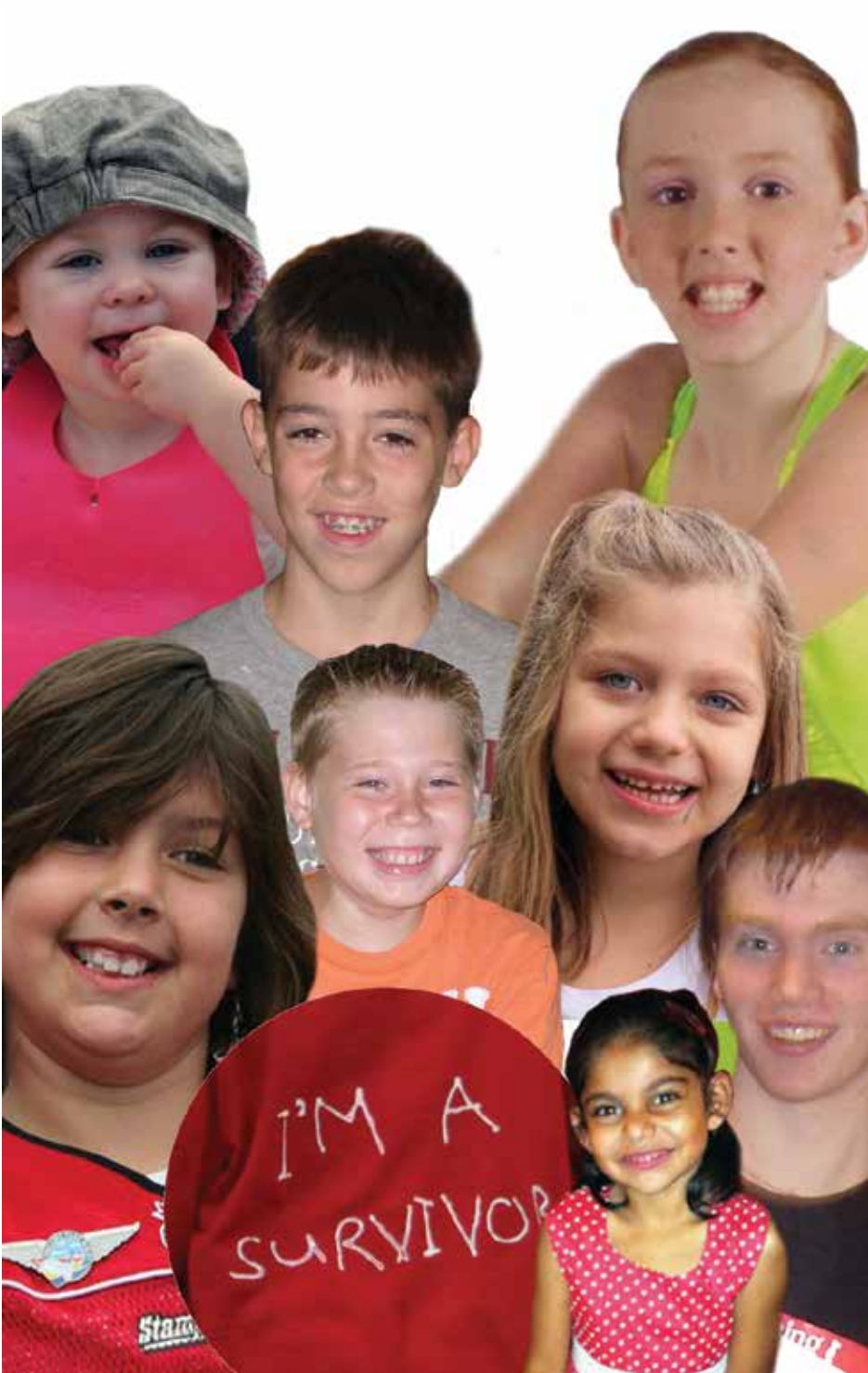
HEART &
STROKE
FOUNDATION

CANADIAN
Stroke
BEST PRACTICE
RECOMMENDATIONS

This guide is dedicated to all families who have experienced childhood stroke. Our precious children teach us so much about strength, courage and hope.

“May we choose happiness like Gabrielle did: wholeheartedly and unconditionally and despite any struggle, big or small”

Nikki, Mother of Gabrielle, Oakville.



ABOUT THIS GUIDE

This guide is designed to provide basic information about stroke and stroke care to families of children who have had a stroke. This guide is an educational resource based on the Canadian Stroke Best Practice Recommendations, current research and expert opinion. Research about stroke in children and babies is still developing; much of the information in this guide comes from stroke experts and from families who have experienced childhood stroke and are sharing their stories.

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WHAT IS A STROKE?

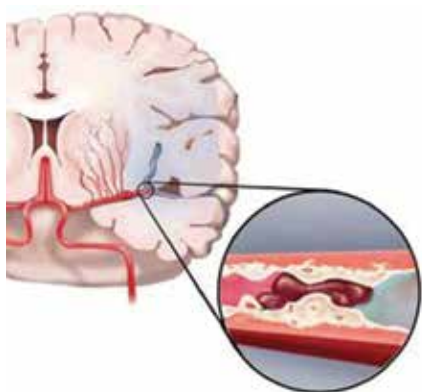
There are two main types of stroke that occur at any age: ischemic stroke and hemorrhagic stroke.

Ischemic stroke: A stroke that occurs when an artery which supplies blood to an area of the brain narrows or becomes blocked. This results in a decreased amount of blood reaching the area of the brain beyond the blockage, resulting in brain damage.

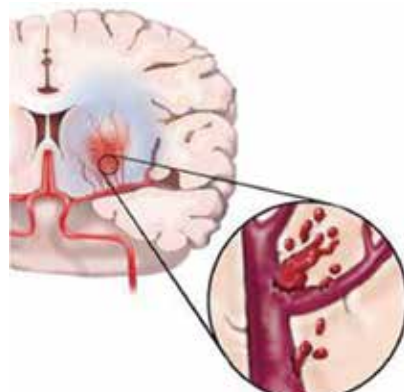
Cerebral Venous Sinus Thrombosis: A condition where a blood clot forms in a vein inside the brain (as opposed to in an artery). A stroke can occur if the blood clot blocks the flow of blood within the brain.

Hemorrhagic stroke: A stroke caused by the breakage of a blood vessel within the brain that often causes damage to the brain tissue.

Ischemic stroke



Hemorrhagic stroke



HOW COMMON ARE STROKES IN INFANTS AND CHILDREN?

To understand stroke we need to consider two different stages when stroke can occur:

Perinatal Phase: before birth up to age 28 days. The perinatal time-frame therefore includes both fetal stroke (before birth) and newborn or neonatal stroke (at birth or within the first 28 days of life).

The highest risk for stroke occurs in the first year of life and in the elderly. At least one newborn will have a stroke for every 2300 live births each year. The risk of all perinatal stroke is likely even higher. This means that 200 to 300 Canadian children will experience a perinatal stroke each year.

Childhood Phase: starts at 29 days of life and continues to age 18 (after turning 18 years old, children usually move to adult medical care).



The number of children diagnosed with stroke is increasing.

This is happening for several reasons. Increased awareness that pediatric stroke occurs has led to more prompt investigations when a child presents with signs and symptoms of stroke. We now have improved diagnostic tests like more advanced magnetic resonance imaging (MRI) scans that can better identify stroke in children; and, more children are surviving serious diseases that happen when they are young (such as leukemia and heart problems), which may result in an increased risk of stroke. In addition, the prevalence of risk factors for stroke in children is increasing.

HOW DOES PEDIATRIC STROKE DIFFER FROM ADULT STROKE?

Stroke can affect children and adults at any age. The causes of stroke in children are different from in adults. Symptoms of stroke in newborns and pre-school children are often different from adults because a child's brain is still developing. However, in older children, the signs and symptoms of stroke are very similar to those in adults and depend upon the area of brain involved. For newborns and children, the diagnosis is often delayed or missed because usually you would not think of a stroke as the first explanation for the symptoms.

BE AWARE and BE INFORMED!

Stroke will affect 3 to 6 of every 100,000 children over the age of 28 days. This is more common than brain tumors in children.

Approximately the same number of children will experience strokes caused by blockages (ischemic) as strokes caused by bleeding (hemorrhage).

CHARACTERISTIC STROKE IN ADULTS CHILDHOOD STROKE PERINATAL STROKE

Most Common Types of Stroke

- 80% caused by blockage and blood clots;
- 20% caused by bleeding into the brain
- ~50% caused by blockage and blood clots;
- ~50% caused by bleeding into the brain
- 80-90% are blockages of either arteries or veins
- 10-20% are bleeding strokes

Major Risk Factors and Causes of Stroke

- High blood pressure
- Diabetes
- High cholesterol
- Smoking
- Abnormal heart rhythm (atrial fibrillation)
- Birth defects
- Heart problems
- Problems with blood vessels
- Infections (e.g. meningitis)
- Head trauma
- Blood disorders (such as sickle cell, anaemia or leukaemia)
- Dehydration
- Most causes remain unknown
- Congenital heart disease
- Disorders of the placenta
- Blood clotting disorders
- Infections (e.g. Meningitis)
- Dehydration

Common Signs and Symptoms

- Numbness or weakness in face, arm, leg
- Trouble speaking
- Vision problems
- Sudden and severe headache
- Sudden dizziness
- Weakness on one side of the body
- Trouble speaking
- Severe Headache
- Seizures,
- Trouble staying awake and alert outside of normal sleeping and nap times
- Newborns: Seizures
- Infants: Weakness on one side of the body typically seen between 4-8 months of age:
 - Hand preference: children should not show a consistent handedness before the age of one year
 - Hand fisting or toe clenching on one side
 - Decrease use of one side of the body

MORE RESEARCH IS NEEDED TO UNDERSTAND OTHER RISK FACTORS FOR STROKE IN CHILDREN

TAKE ACTION

All patients with symptoms of stroke, regardless of age, need to be assessed immediately by health-care professionals. It is very important that families **take immediate action and call 9-1-1** or the emergency response number if they see sudden signs of stroke or sudden changes in their child’s neurological health status. It is **much safer to have an ambulance** take your child to the hospital; ambulances take patients to hospitals that have stroke services, and they can notify the hospital so the doctors and nurses are ready to help when you arrive. Infants with early hand preference before 12 months should see their family doctor or pediatrician and request a referral to a pediatric neurologist.

HOW DOES THE BRAIN WORK?

The brain is made up of three major parts: brain tissue, blood and cerebral spinal fluid.

The brain is located inside the skull, which is a closed, rigid container that protects the brain. The brain takes up about 80-90% of the space inside the skull. Blood, which nourishes the brain, and fluid called cerebral spinal fluid (CSF), which helps to protect the brain take up the remaining space. The brain weighs about 2% of your total body weight, and receives 15 - 20% of the body's blood supply.

The brain is unable to store nutrients such as sugar or oxygen, so a constant supply of blood is needed for the brain to function. The brain can become damaged when something changes the flow of blood.

The brain contains about 100 billion neurons and is considered the 'control centre' for the whole body. The brain has 2 sides, a left side and a right side (called hemispheres) that are connected to each other by millions of nerve fibres. The right hemisphere controls how we move and feel on the left side of the body and the left hemisphere controls the right side of the body.

Thalamus:

Sensory
Processing
Movement

Hypothalamus:

Body Temperature
Emotions
Hunger
Thirst
Circadian Rhythms

Limbic System:

Emotions
Memory

Hippocampus:

Learning
Memory

Mid Brain:

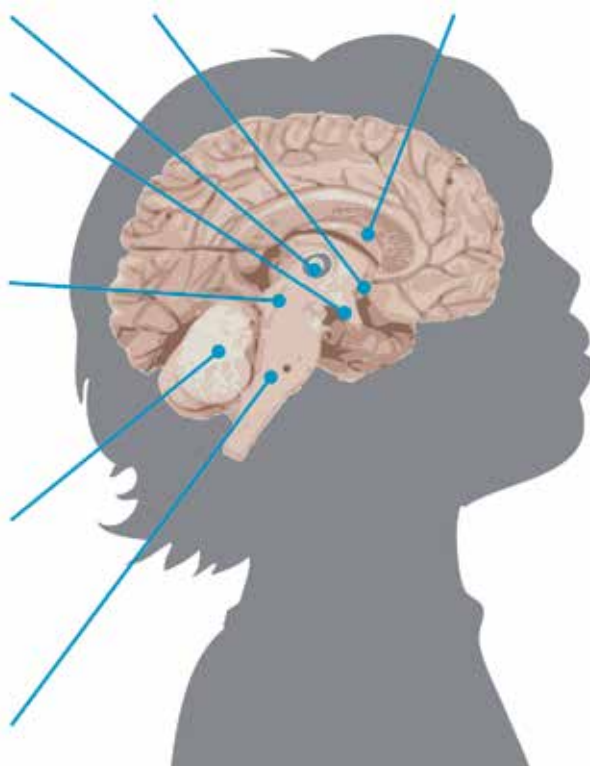
Vision
Auditory
Eye Movement
Body Movement

Cerebellum:

Movement
Balance
Posture

Brain Stem:

Breathing
Heart Rate
Blood Pressure



HOW IS A STROKE DIAGNOSED IN INFANTS AND CHILDREN?

To diagnose a stroke in infants and children, the signs and symptoms above must first be recognized and the diagnosis considered. Brain pictures are then taken (see below) to confirm the presence and type of stroke. To find out what might have caused the stroke, health-care professionals including stroke team doctors and nurses speak to children and parents to obtain relevant information on:

- The mother's health and pregnancy
- Family history of parents and blood related relatives
- The child's birth history, medical problems or illnesses
- The child's developmental milestones - when your child started to crawl, walk, speak
- Normal behaviours and learning level. They will ask if you have noticed any recent changes.
- Details about neurological symptoms
- Related medical issues: infections, trauma, medications, etc

The physical exam along with the child's health history and results from specific tests will help health-care workers find the right diagnosis and plans for treatment. These tests may include:

Brain Scan (CT/MRI): There are many types of brain scans, including a computed tomography scan (CT Scan), a magnetic resonance imaging scan (MRI), or an ultrasound. A brain scan is used to show health care professionals the brain tissue, blood flow and fluid inside the skull. These are often the first tests used when doctors think a child has had a stroke. These images can show whether a stroke was due to a blood clot (an ischemic stroke) or bleeding (a hemorrhagic stroke). Sometimes a dye is also used to make the artery and vein structures in the brain easier to see, and also to see if a blockage is present in the arteries or veins as a cause for the stroke.

Cerebral Angiogram: This test looks specifically at the blood vessels in the brain. A special dye and X-rays show how blood is flowing through blood vessels,

It is important to make sure these tests are explained to your child in words they will understand. Describe the equipment, the sounds, and environment they will experience. Make sure they know they will not be alone.

and this helps to detect and diagnose any problems with the blood vessels in the brain.

Blood Tests: A number of blood tests may help identify potential causes of a child's stroke. These include looking at the blood cell counts and the blood clotting system as well as tests for infections or other diseases that might predispose a child to stroke.

Echocardiogram (Echo): This ultrasound creates moving pictures of the heart. It can identify heart problems that lead to stroke such as structural problems, poor functioning, blood clots, or infections.

Electrocardiogram (ECG): Stickers are put on the chest to measure the heart's electrical activity and help exclude a problem with the heart rate or rhythm that might lead to stroke.

Electroencephalogram (EEG): Stickers are placed on the scalp and connected to wires that are hooked up to a machine. The machine is able to show information about the child's brainwaves and might be used to help understand seizures (excess electrical activity in the brain that can happen after a stroke).

Physical Exam

All children with stroke require a comprehensive neurological and medical examination.

Some tests and assessments may include examining a child's overall health, their development, and how they behave, speak, walk and balance as well as test reflexes, strength, sensation and vision.



STROKE IN INFANTS

ISCHEMIC STROKE

Perinatal ischemic stroke

In children, the time period that holds the highest risk for stroke is during the perinatal period. This time period begins about halfway through pregnancy, includes birth, and continues up to age 28 days. There are different kinds of ischemic stroke that can happen during the perinatal period.

1. Neonatal Arterial Ischemic Stroke (NAIS)

This is a sudden blockage of an artery, preventing blood from reaching a specific area within the brain. Usually this occurs around the time of birth. Symptoms of seizures are often noticed within the first days of life, prompting physicians to order a brain scan to confirm the diagnosis of this type of stroke.

2. Presumed Perinatal Ischemic Stroke (PPIS)

Babies who have had a stroke before birth or do not have seizures at birth usually look entirely normal because the brain is only just developing. Therefore, the signs of these strokes are only recognized later in infancy. Parents usually notice weakness or clear early hand preference on one side of the body around 4-6 months. A brain scan then confirms that a stroke has happened during the perinatal period. There are two common types of PPIS:

2a. Arterial Presumed Perinatal Ischemic Stroke (APPIS)

These are caused by a sudden blockage of an artery in the brain which occurs in the perinatal period. Therefore, these are very similar to NAIS, the only difference being the age when signs are recognized.

2b. Periventricular Venous Infarction (PVI)

This type of stroke usually occurs during pregnancy or in premature infants. A collection of blood vessels that helps to nourish a growing brain can start to bleed. The blood within the ventricle can put pressure onto veins beside the ventricles, which are required for blood to drain away from that part of the brain. The pressure causes blood flow in the vein to be blocked. This usually damages the pathways responsible for movement in the brain, resulting in weakness on the other side of the body recognized in infancy.

“You know your child better than anyone else. You know what is normal for them and what is not. People will tell you that infants are all different in terms of when they reach their milestones. Trust your instincts and do not be afraid to speak up if you feel something is not right.”

— **Andrea**, Mother of Paige, Calgary



This is Paige and her father, Chris. Paige experienced a perinatal stroke.

RISK FOR STROKE RECURRENCE AFTER PERINATAL STROKE

The risk for having another stroke is very low in children diagnosed with perinatal stroke. Recurrence risk is estimated to be less than 1%. A few exceptions include children who have ongoing risk factors for stroke such as complex congenital heart disease or rare serious blood clotting disorders. Your pediatric stroke specialist can provide you with more information regarding your child's stroke recurrence risk.

VERY IMPORTANT!

The recurrence risk for subsequent pregnancies for the same couple also appears to be extremely low. While this has not been well studied, one Canadian study of over 400 children with perinatal stroke does not include a single case of recurrence within the same family.

“Studies are showing that children with stroke are not ‘little adults’ and have very different causes, symptoms and outcomes after stroke.”

— **Dr. Gabrielle deVeber**, Pediatric Neurologist, Toronto

“More research is needed to better understand the exact timing and causes of perinatal strokes; to determine the most effective treatment and prevention strategies; and to support long-term recovery to maximize outcomes for the child.”

— **Dr. Adam Kirton**, Pediatric Neurologist, Calgary

SIGNS AND SYMPTOMS

Neonatal Arterial Ischemic Stroke (NAIS)

Newborns who have had a stroke may not show any obvious signs and symptoms initially. The most common signs and symptoms may include:

- Most children with NAIS will present with seizures. Seizures may affect one side of the body more than the other;
- Sleepiness and drowsiness (lethargy) that is more than expected for an infant;
- Sleep apnea, where the infant stops breathing for short periods of time during sleep.

Presumed Perinatal Stroke:

- Weakness in one side of the body (hemiparesis) that is typically noticed as the infant develops between 4 and 8 months of age;
- Sometimes the only sign of hemiparesis is that children less than one year of age start to favor using their right or left hand or foot too early - normally this does not happen until after the first year of life;
- Another sign of hemiparesis can be constant fisting of one hand and clenching toes of one foot;
- Children may also experience other developmental delays or seizures.

DIAGNOSIS

- A computed tomography scan (CAT scan or CT scan) or a Magnetic Resonance Imaging scan (MRI) should be completed to confirm a diagnosis of stroke; and,
- Investigations into the possible causes for the stroke should be done, including having an accurate history of the pregnancy and birth, X-rays, heart tests, and blood tests.

This is *Gabrielle*. Gabrielle experienced a perinatal stroke.





This is *Zachary*. He experienced a perinatal stroke.

TREATMENT

- If symptoms of seizure are seen, the infant should be taken to the hospital immediately for assessment, diagnosis and treatment.
- Treatment for perinatal stroke usually does not include administering blood thinner medications (called antiplatelets or anticoagulants) to reduce further clots from forming. However, if the stroke is due to congenital heart disease or a serious blood-clotting disorder, sometimes these medications are needed.
- Medications and other treatments may be recommended to help treat the symptoms (e.g. to control seizures) or correct the cause of the stroke, such as rehydration, antibiotics for meningitis, and, medication or surgery to correct heart abnormalities.
- Rehabilitation is generally believed to improve outcomes over the long-term.

“This isn’t what I expected for my first born but Zach is so beautiful and teaches us so many things all the time, we couldn’t imagine him any other way!”
 — **Charlene**, Mother of Zachary, Winnipeg

CHILDHOOD ISCHEMIC STROKE

ISCHEMIC STROKE

SIGNS AND SYMPTOMS

Very sudden onset of the following symptoms in children should be considered a possible stroke:

- Trouble speaking with slurred or inappropriate speech, or inability to speak at all
- Vision problems, such as sudden blindness or blurred vision
- Numbness, weakness or inability to move one side of the body
- Sudden headache
- Seizures
- Sudden change in alertness and ability to think clearly
- Dizziness, loss of balance, nausea and/or vomiting, together with some of the above symptoms

DIAGNOSIS

- A Magnetic Resonance Imaging scan (MRI) or a computed tomography scan (CAT scan or CT scan) should be completed to confirm a suspicion of stroke; an MRI is better at identifying stroke in children, especially in the first 24 hours after onset of symptoms.
- Detailed family history regarding stroke, heart disease and other vascular diseases;
- Physical examination;
- Investigations into the possible causes for the stroke may also be done, including having an accurate history of the pregnancy and birth, X-rays, heart tests, and blood tests.

This is *Tyra* and her family. Tyra experienced a childhood stroke.



“We all celebrated when our daughter met her personal rehabilitation goal of doing her own ponytail using both hands.”

— **Global News
Calgary,**

August 19, 2011

The cause of stroke during childhood can go undetermined in approximately 10% of cases

TREATMENT

- **Call 9-1-1.** The child must be taken to an emergency department immediately for assessment.
- Treatment for childhood ischemic stroke usually includes medications, such as Aspirin™ or blood thinners (called antiplatelets or anticoagulants), to prevent further clots from forming.
- Medications and other treatments may be recommended to help correct the cause of the stroke, such as treatment for heart problems, rehydration, or treatments for blood and blood vessel diseases.
- Rehabilitation is generally believed to improve outcomes over the long-term. All children diagnosed with ischemic stroke should be assessed by the rehabilitation team.

WHAT IS A TRANSIENT ISCHEMIC ATTACK?

A Transient Ischemic Attack, or TIA, is a temporary blockage related to the blood flow going to the brain. A TIA will usually last from two to 15 minutes, but occasionally symptoms can last as long as a day (24 hours). TIAs do not cause long-term problems, however it may be a warning sign that a patient is at an increased risk for a stroke.

SIGNS AND SYMPTOMS

- Similar signs and symptoms for ischemic stroke noted above.

There is a 6% to 14% chance that a child who has had a childhood stroke may have a recurrence; children who have had a stroke are also at an increased risk for ‘mini-strokes’ (transient ischemic attacks), and ‘silent strokes’ that happen without symptoms we can see.

DIAGNOSIS

- Similar diagnostic steps are required to diagnose a TIA as for ischemic stroke, noted above.
- It is important that the diagnosis of TIA versus ischemic stroke be made when the event occurs, and also to investigate whether the signs and symptoms are caused by a stroke or TIA, or caused by another neurological problem that can ‘mimic’ stroke (such as seizures or migraine headaches).
- For TIA patients, preventative medical treatments (described below) should be started as soon as medically appropriate in order to reduce the risk of a more serious stroke in the future.

TREATMENT

- **Call 9-1-1.** The child must be taken to an emergency department immediately for assessment. You may not know it is a TIA at first, therefore it is important that anyone showing symptoms of possible stroke be taken to hospital by ambulance as soon as the symptoms begin.
- Treatment for childhood TIA may include medications, such as Aspirin™ or other antiplatelet medications, or stronger blood thinners (called anti-coagulants), to prevent further clots from forming and another TIA or stroke from occurring.
- Medications and other treatments may be recommended to help correct the cause of the TIA, such as treatment for heart issues, rehydration, or treatments for blood and blood vessel diseases.
- Rehabilitation may or may not be required for a child who has had a TIA. All children should be assessed for their rehabilitation needs before leaving hospital or, for children not admitted to hospital, within two weeks of leaving the emergency department.

There is clear evidence that TIAs indicate a risk of a future stroke, and 20% of future strokes can happen within two days of the TIA.

“Things that sound too good to be true usually are – there are many people who would promote unproven and potentially dangerous “treatments” for children with stroke.

Be very careful what you read on the internet and review all information with your child’s neurologist.”

— **Dr. Adam Kirton**, Pediatric Neurologist, Calgary



This is *Gabrielle* and her brother and sister. Gabrielle had a perinatal stroke.

WHAT IS CEREBRAL VENOUS SINUS THROMBOSIS (CVST)?

An additional rare condition called Cerebral Venous Sinus Thrombosis (CVST) may also occur and cause a stroke. CVST is the presence of a blood clot in the veins and/or sinuses (channels) located in the brain. These could involve either veins near the outer surface of the brain (superficial) or veins deeper inside the brain tissue. This type of clot can block the drainage of blood and fluids from the brain which can result in swelling, increased pressure or bleeding in the brain. This is a rare type of stroke that happens in 0.67 out of 100,000 children, and it usually happens more often in infants under the age of one year than in older children. CVST can also exist and not always cause a stroke.

SIGNS AND SYMPTOMS

Signs and symptoms depend on where in the brain the clot develops, how fast the clot develops, how big the blockage is, and the age of the child. The signs and symptoms are similar to many other conditions, which can make them difficult to diagnose.

“It is possible to live a fulfilled and joyful life with a diagnosis of childhood stroke. Being informed and feeling supported will help families move beyond the diagnosis and back into meaningful living”

— **Nikki**, Mother of Gabrielle, Oakville

Neonatal Cerebral Venous Sinus Thrombosis

CVST is harder to diagnose in neonates as signs and symptoms are typically very general or unclear. They often include seizures, swelling of the brain, difficulty with feeding, and more sleepiness than is normal for a newborn (lethargy).

Childhood Cerebral Venous Sinus Thrombosis

Signs and symptoms of CVST in children include but are not limited to seizures, headache, vomiting, fatigue, sleepiness, decreased alertness, fever and dehydration.

DIAGNOSIS

- A detailed family history regarding stroke, heart disease and other vascular diseases.
- A brain scan (MRI with MR Venogram, CAT or CT scan, or CT Venogram) is needed to diagnose CVST because these scans have the ability to check blood flow in the brain and detect clots, swelling of the brain, damage to brain tissue and other abnormalities.
- Physical examination.

TREATMENT

- Common treatments include blood thinning medications to help dissolve clots and prevent further ones from forming.
- Administering fluids to correct dehydration.
- Diagnosis and treatment of other medical conditions that may have caused the CVST to happen.
- If there is swelling in the brain, medications can be used to reduce the pressure, or a small tube can be placed in a ventricle of the brain to drain the extra cerebral spinal fluid (CSF) fluid. This tube is called a shunt.
- Medications to help stop seizures and slow down swelling in the brain.

This is *Brookelyn*. Her story is on the right.



HEMORRHAGIC STROKE

Hemorrhagic stroke occurs when there is a weakening of a blood vessel, usually an artery, that starts to leak or breaks open, and causes bleeding into the brain. Bleeding caused by a broken blood vessel can cause the pressure inside the skull to increase. The brain can be damaged if this pressure becomes too high and starts to squeeze the brain tissue. The broken blood vessel can also stop blood from flowing to other parts of the brain.

SIGNS AND SYMPTOMS

Very sudden onset of the following symptoms in children should be considered a possible stroke:

- Sudden severe headache and often projectile vomiting;
- Sudden change in level of consciousness (confusion, decreased alertness and/or suddenly becoming very sleepy);
- Signs and symptoms of stroke such as sudden weakness or numbness on one side of body, vision problems or speech problems; and
- Seizures

DIAGNOSIS

- A computed tomography scan (CAT scan or CT scan) or a Magnetic Resonance Imaging scan (MRI) should be completed to confirm a diagnosis of hemorrhagic stroke.
- Investigations into the possible causes for the stroke may also be done, including having an accurate history of the pregnancy and birth, X-rays, heart tests, and blood tests.

About half of all neonatal and childhood strokes are caused by bleeding (hemorrhage) into the brain.

“When I first got to Brookelyn’s side, I immediately noticed her face was drooping and that she was drooling. She was tired and seemed confused. I was confused by her symptoms. What scared me was when her caregiver told her that her mom was here, she looked me dead in the eyes and said, ‘Where? Where is my mom?’ You don’t ever think a five-year-old can have a stroke, but had I seen the same symptoms on a 65-year-old woman, I would have known immediately.”

— **Cortney**, Mom of Brookelyn, Calgary

TREATMENT

- **Call 9-1-1.** The child must be taken to an emergency department immediately for assessment.
- Surgery may be needed to repair an artery, drain the extra blood from the brain and/or decrease any extra pressure in the skull.
- Medications and other treatments may be administered to help correct problems caused by the hemorrhagic stroke, such as fever or dehydration.
- All children should be assessed for their rehabilitation needs before leaving the hospital or, for children not admitted to hospital, within two weeks of leaving the emergency department.





This is *Shamus* (right) and his brother. Shamus experienced a childhood stroke.

IMMEDIATE CARE AND RECOVERY: STROKE CARE IN HOSPITAL

Who will be on our care team?

Most children who have had an acute stroke will be admitted to hospital for further tests to determine the causes and impact of the stroke and to provide treatment. Ideally, children who have had a stroke should be cared for in a hospital with pediatric stroke expertise.

All children with stroke who are in hospital should be cared for using specific protocols created for children with stroke using the best available research information and health-care expertise.

Many different types of health-care professionals will be involved in the care of children with stroke while in hospital and when they start rehabilitation. They all work together as a team. Family members and patients are very important members of the team and should be active participants in care planning and decision-making.

“As a parent you constantly worry. We are lucky he has no long-lasting deficits. I do think parents need to get together and talk. Support from others who really understand is so important, especially in the early days.”

- **James**, Father of Shamus, Winnipeg.

Team members may include:

- Neurologists who specialize in stroke
- Primary Care Physicians
- Pediatricians
- Nurses
- Other medical specialists (depending on the underlying cause of stroke)
- Patients and their family members
- Speech Language Pathologists
- Exercise and Rehabilitation Assistants
- Physiatrists – doctors who specialize in rehabilitation
- Recreation and Play Therapists
- Physical Therapists
- Social Workers
- Occupational Therapists
- Dietitians
- Pharmacists
- Child Psychologists

Each of these team members will play an important role in providing care for your child. Continue to ask them questions throughout your care journey.

An important role of each member of the health-care team is to educate families about their child's diagnosis of pediatric stroke. Sometimes it is difficult for health-care workers to be able to determine the exact causes of stroke and the extent of stroke recovery. Some important questions to ask your health-care specialists can include:

- What effects will the stroke have on our child's growth and development?
- What will our child's recovery be like?
- What do we need to consider for our child once he or she is discharged from the hospital?
- What types of financial, rehabilitation and educational supports are available for my child?
- What services and resources are available in our community to help a child who has had a stroke?
- Who should I call when I have more questions?

“While the newborn brain is vulnerable to damage it also has an incredible capacity for repair. Our goal is to identify ways to promote repair and recovery.”

— **Dr. Steven Miller**, Pediatric Neurologist, Toronto, Ontario

REHABILITATION AND RECOVERY FOR A CHILD DIAGNOSED WITH STROKE

The brain of a child and infant is still growing and developing and constantly learning things which are new. Rehabilitation following stroke or transient ischemic attack can likely lead to significant improvements in long-term outcomes for your child.

The length of rehabilitative treatment will be different for everyone, and different amounts or types of therapy may be needed at different times throughout growth and development.

All children diagnosed with stroke should have a detailed assessment by health-care professionals who specialize in rehabilitation. The rehabilitation team will be able to determine the types of therapy a child could benefit from and the best locations where children can receive that care. The stroke rehabilitation team may include many of the team members we have listed in the section on stroke care in hospital.

“The system is only as good as you make it. You need to go out to find the resources your child needs and you really need to listen to what the Occupational Therapists and Physical Therapists say about the exercises. The exercises are so important and you need to keep it up and do them.”

— **Charlene**, Mom of Zachary, Winnipeg

This is *Zachary*. He experienced a perinatal stroke.



It is normal to feel overwhelmed by all the assessments during the early days following a diagnosis of stroke in a child. All the health-care professionals who see a child are working together as a team to ensure each child receives the best care possible. Both the family and the health-care team will work together to form an individualized plan of care for the child. It is important that family members be involved in the planning of care and understand the details and requirements to help the child have the best recovery possible.

It is important that rehabilitation therapy begin as soon as possible following a stroke. Rehabilitation should be started in the hospital and continued once a child leaves hospital. After discharge from hospital, rehabilitation can be provided at home, in an outpatient clinic that is part of the hospital or at specialized pediatric rehabilitation centres.

Rehabilitation sessions work to improve functions that were affected by the stroke and assist in helping the child to adapt to physical or cognitive changes. Sessions may also include the development of skills that will be needed to be independent at school or at play. Cognitive assessments, which examine the child's ability to learn and detect any learning difficulties, can help in planning educational programs once the child reaches school age or returns to school.

It is good to get all family members involved in a child's rehabilitation. It is important that siblings become involved, and are given a chance to ask questions and get honest, age-appropriate answers.

Your health-care team should continue to provide information and education throughout rehabilitation and during recovery. The educational needs of each family are unique and tend to change throughout rehabilitation, recovery, and as the child reaches new developmental milestones.

This is *Aidan* and his physical therapist. Aidan had a stroke at age 16.



Important things to know during rehabilitation

- The stroke team will work with you and your child to develop a rehabilitation plan. This plan should be updated as the child progresses and improves.
- Parents and family members should receive training by the rehabilitation team on how to help a child during rehabilitation and recovery.
- The stroke team should work with families to prepare for a child's return home. You may need to adapt your home to make it safe and accessible for your child.
- When you leave hospital, rehabilitation should continue and may occur in different settings such as an outpatient clinic, a community program, in your home, and at school.
- If a child's symptoms change or seem to become worse during rehabilitation or after the child leaves hospital, notify your health-care team immediately.

ONGOING STROKE CARE

Stroke care does not end when you leave the hospital or the rehabilitation centre. Your child will continue to be seen by their pediatric stroke specialist and/or other physicians to assess and follow up on their recovery. Each child's recovery from stroke is unique, and the healthcare team is there to make sure your child has the services they need in order to have the best recovery possible from their stroke. There are more and more resources being developed to help families and children overcome some of the challenges they may face in having a diagnosis of stroke. Ask your health-care specialist to help you navigate what resources are available for you and your child.

“We used music a lot. Aidan seemed to sing easier than talk. You know your child better than anyone. Together you'll figure out what works for you and your family. Don't forget to take time to play with your child and have fun.”

— **Peggy,**

Mother of Aidan,
Newfoundland

“We also make sure to play with her a lot and concentrate on her weak side to increase the awareness she has. She has gone from not feeling anything if you tickled her foot to being ticklish on that side.”

— **Andrea,** Mother of
Paige, Calgary

Here are some points to consider discussing with the health-care team in helping to plan for your child's ongoing needs after a diagnosis of stroke.

- Who will continue to follow up on my child's recovery?
- How are appointments booked, how do I contact those individuals?
- What signs and symptoms should I be looking for in my child and who do I contact with questions or concerns?
- Will my child be taking any medications or receiving other treatments once we are at home? What do I need to know about such medications and treatments.
- What do I need to consider as my child either returns or enters school?
- Is there a local support group of other families that have experienced pediatric stroke? How can I contact them?

WHAT FAMILIES CAN DO TO REDUCE THE RISK OF PEDIATRIC STROKE AND STROKE IN ADULTS:

Although causes of stroke are generally different for children, lifestyle management issues are equally important for the pediatric population, particularly as the long-term risk of recurrence for children is much higher. When these children become adults, if they are obese, smokers or have other risk factors for stroke and heart disease, the risk of another stroke is greater.

REGULAR EXERCISE IS IMPORTANT:

All children should have at least one hour of exercise every day.

For children age 5-11, try some of these activities:

- Play tag – or freeze-tag!
- Go to the playground after school.
- Walk, bike, rollerblade or skateboard to school.
- Play an active game at recess.
- Go sledding in the park on the weekend.
- Go “puddle hopping” on a rainy day.

For children age 12-17, try some of these activities:

- Walk, bike, rollerblade or skateboard to school.
- Go to a gym on the weekend.
- Do a fitness class after school.
- Get the neighbours together for a game of pick-up basketball, or hockey.
- Play a sport such as basketball, hockey, soccer, martial arts, swimming, tennis, golf, skiing, or snowboarding.

HEALTHY DIET:

Decrease sodium (salt) & Eat lots of fruits and vegetables

Following Canada's Food Guide helps children grow and thrive.

Young children have small appetites and need calories for growth and development.

- Serve small nutritious meals and snacks each day.
- Do not restrict nutritious foods because of their fat content. Offer a variety of foods from all food groups.
- Most of all... be a good role model.

SMOKING:

Limit your risk by avoiding or quitting smoking, avoiding second-hand smoke and making your home and car smoke free.

Talk to your teen about the health risks of smoking and how to resist peer pressure.

OBESITY AND BODY WEIGHT:

Maintaining a healthy weight is important for growing children. This can be done by:

- Being physically active
- Making healthy food choices
- Limiting how much sugar you eat and drink
- Eating reasonably-sized portioned meals
- Avoiding unhealthy food temptations in the house.

BLOOD PRESSURE:

Having your blood pressure checked should be a normal part of any medical check-up.

High blood pressure can increase your risk of stroke. If high blood pressure is discovered, tests may be done to find out what is causing the high blood pressure and medications may be used to treat it.

Family Support Groups

Family support groups that are specific for families who have experienced childhood stroke are made up of individuals who understand your situation and can talk to you about their own experiences.

These support groups are new in Canada and are just getting started. Parents should ask their health-care team whether there is a support group in their area and how to make contact with the group.



GROWING UP AFTER A STROKE

RECOVERY AND MOVING FORWARD

FAMILY ROLES

Every family member plays an important role in a child's recovery from stroke. Family members can do many normal activities to help a child recover. It is important that family members and care providers gain as much education and understanding of stroke as possible.

Here are some things that families can do together:

- Create an enriching environment. Read a book, do a puzzle or a craft.
- Do activities together that need two hands! Try shaping cookies from cookie dough and gradually work up to more challenging tasks.
- Share in lots of laughs! Positive emotions and laughter help prepare the brain to be ready to learn.
- Play a video game (but be careful if seizures are a problem for the child)
- Go on outings together.

EMOTIONAL AND BEHAVIOURAL HEALTH

Stroke can have a considerable effect on a child's emotions and behaviour. Depression, anxiety, other mood changes, attention problems, and memory problems can all occur at some point after a stroke. Some of these changes may not be seen until the child grows and develops. Changes such as in the inability to do progressively complex math, problem solving or difficulty with reading comprehension may start to show up at school.

It is important for parents to watch for these changes and share concerns with their health-care team right away. Prompt treatment for depression and other changes will help improve the child's overall recovery and his or her ability to participate in rehabilitation. Resources are available to help your child overcome these challenges in school and as she or he grows and matures.

Parents and other family members are also at risk of experiencing depression when a child has had a stroke. Parents are strongly encouraged to talk to their health-care team about their own emotional needs so that they are better able to cope and be able to support their child and family.

SCHOOL-AGE CHILDREN: RETURNING TO THE CLASSROOM

Returning to school full-time following a stroke is a major milestone and needs to be carefully planned. A slow return may be good. It is wise to keep in touch with friends during the stroke recovery period as this can make settling back into school easier.

It is important to be patient during the transition back to school as some things may seem more difficult at first than they were before the stroke.

It may help if the teachers and parents of their classmates are informed of your child's progress; if they are aware of any differences that classmates may notice (such as a difference in walking or a change in speech), they can speak to their child about the importance of acceptance and being supportive. Talking about these changes before returning to school may make the transition easier. Members of your medical team may have suggestions.

PALLIATIVE CARE

Palliative care can complement life-prolonging or disease-modifying therapies post-stroke and need not be reserved for those whose death is imminent. Palliative care aims to prevent and relieve physical, social, psychological, or spiritual suffering of stroke patients and their families. Rarely, a stroke is life-threatening and for such children, complications can happen along with the stroke that can cause a child to be uncomfortable. Often, palliative care can be provided to keep the child comfortable during this time. End-of-life care or terminal care may be offered in these cases.

“Keep all your records organized and available. Once you get yourself organized, you’ll feel more in control and less overwhelmed.

Prepare a package of important information to provide everyone who will be working with your child (such as, teachers, healthcare workers, and coaches).”

— **Cortney**, Mom of Brookelyn, Calgary



PARENT TO PARENT:

Families from all over Canada have generously shared their stories with us. The following are some words of wisdom from these families on how to move forward with success.

- **Advocate** - in all parts of your child's life. They will need it - even with the experts.
- **Organize** - keep all records and information organized and available. This will help you feel more in control of you child's health and the challenges you will face.
- **Create** - an information sheet about your child to give to the school and leaders of all their other activities. Include emergency contacts, and an action plan in case a change in your child's health occurs.
- **Notify** - register with MedicAlert and have notification jewelry made for your child
- **Plan** - work closely with your child's teachers and principal to create a specialized education plan. Include members of your health-care team such as an occupational therapist, when needed, to help your child have everything they need to succeed at school.
- **Double Check** - be very careful what you read on the internet and check with your health-care team to verify information.
- **Communicate** - take the time to talk to your child and explain what it means to have had a stroke. Use language your child will understand and adapt the dialogue as they grow and develop becoming involved in different situations.

“The diagnosis of stroke is very overwhelming in the beginning but know that you are not alone and do not lose sight of the big picture. The stroke is just one incident in your child's life and does not define who they are. There will be many challenges that come from this but your child will amaze and astonish you in ways you never expected.”

— **Andrea**, Mother of Paige, Calgary

KID TO KID:

Success stories and words of encouragement from children who have experienced a stroke

“My name is Sydney. Three years ago I had a stroke. I was only in grade two and I didn’t know what had happened. It turns out one of my arteries leading to my brain got squeezed or blocked not allowing blood to get through to my brain. The human brain can’t work properly without blood. **This may seem scary, but it isn’t.** I am fine now. All I have left are some pictures and my memories.”

— **Sydney**, age 11, Winnipeg.



“REACH OUT AND TALK TO OTHERS. YOU ARE NOT ALONE”

“Just because you are limited to one arm or leg doesn’t mean you are limited to life!”

“happiness is in the eyes of the beholder”

“Don’t be afraid to show who you are. I am who I am”

“I AM A SURVIVOR”

“Stroke means challenges, challenges I can overcome!”

“I NEED EXTRA HELP, BUT THAT IS OK TOO”

“Some days are great, and others can be really tough. The good days and a loving family can help conquer the challenges.”

ABOUT THE HEART AND STROKE FOUNDATION

The Heart and Stroke Foundation leads the development and dissemination of the Canadian Stroke Best Practice Recommendations. Within the Recommendations, specific emphasis is placed on areas of stroke care, recovery and education that are unique to the paediatric population. The Foundation's mission is to prevent disease, save lives and promote recovery. A volunteer-based health charity, we strive to tangibly improve the health of every Canadian family, every day. Healthy lives free of heart disease and stroke. Together we will make it happen. heartandstroke.ca



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BEST PRACTICES

For more information on Stroke and Best Practices in Stroke Care visit us at:

www.strokebestpractices.ca

CHILDREN'S STROKE RESOURCES

- **Calgary Pediatric Stroke Program**
www.perinatalstroke.com
- **Sick Kids and Childhood Stroke (aboutkidshealth.ca)**
<http://www.aboutkidshealth.ca/En/HealthAZ/ConditionsandDiseases/BrainandNervousSystemDisorders/Pages/Stroke-Home.aspx>
- **International Pediatric Stroke Study**
<https://app3.ccb.sickkids.ca/cstrokestudy/>
- **Children's Hemiplegia & Stroke Association**
<http://www.chasa.org/>
- **Hemikids**
<http://www.hemikids.org/>
- **Childhood Stroke & Hemiplegia connections of Illinois**
<http://www.cshconnections.org/>
- **Pediatric Stroke Network**
www.pediatricstrokenetwork.com/
- **Bloorview (Rehabilitation)**
<http://www.hollandbloorview.ca/>
- **Erin Oak Kids Centre for Treatment and Development**
<http://www.erinoakkids.ca/>
- **Eating well with Canada's Food Guide**
<http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php>
- **National Stroke Association**
<http://www.stroke.org/understand-stroke/impact-stroke/pediatric-stroke>
- **Heart and Stroke Foundation (kids/teens zone)**
http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.3479025/k.9BB0/KidsTeens_Zone.htm
- **National Stroke Foundation - Australia "Stroke in Children"**
<http://strokefoundation.com.au/what-is-a-stroke/childhood-stroke/>
- **Canadian Pediatric Stroke Support Association**
<http://www.cpssa.org/>
- **International Alliance for Pediatric Stroke**
<http://www.iapediatricstroke.org/home.aspx>

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