

PEDIATRIC STROKES: THE WHO, WHAT, WHEN, AND BEYOND...



A Patient and Family Guide

ABOUT THIS BOOK

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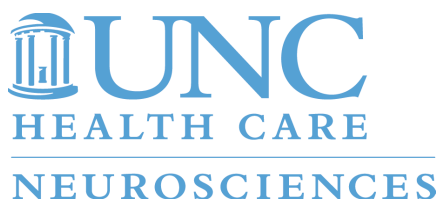


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WHO...

“STROKES CAN HAPPEN AT ANY AGE”

A ‘stroke’ happens when blood flow is blocked, or when a blood vessel breaks in an area of the brain. These changes in blood flow can cause brain cells to die¹. When it comes to stroke, kids are not just little adults⁷. There are two age groups of strokes in kids: Perinatal and Childhood.

PERINATAL:

Week 22 of Pregnancy through 1 Month Old

“It is very important for mothers to know that there is usually nothing they did or did not do during their pregnancy that caused their child’s stroke.”²



Michelle, Perinatal Stroke



Brendon, Perinatal Stroke



Jayden, Perinatal Stroke



Ashton, Perinatal Stroke

CHILDHOOD STROKE:

Infants & Toddlers (1 Month to 3 Years Old)



CHILDHOOD STROKE:

Early Childhood (4 to 12 Years Old)



CHILDHOOD STROKE:

Teenagers & Young Adults (13 to 18 Years Old)

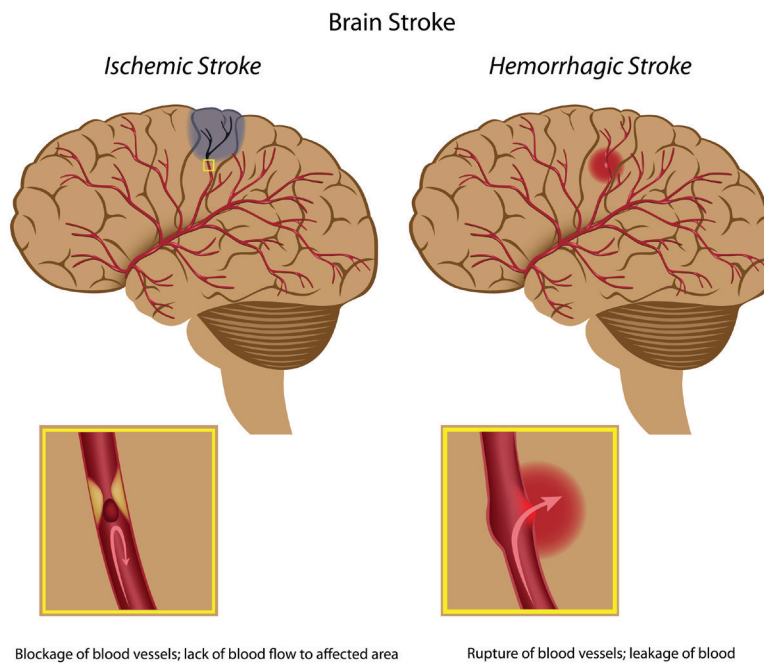


WHAT IS A STROKE?

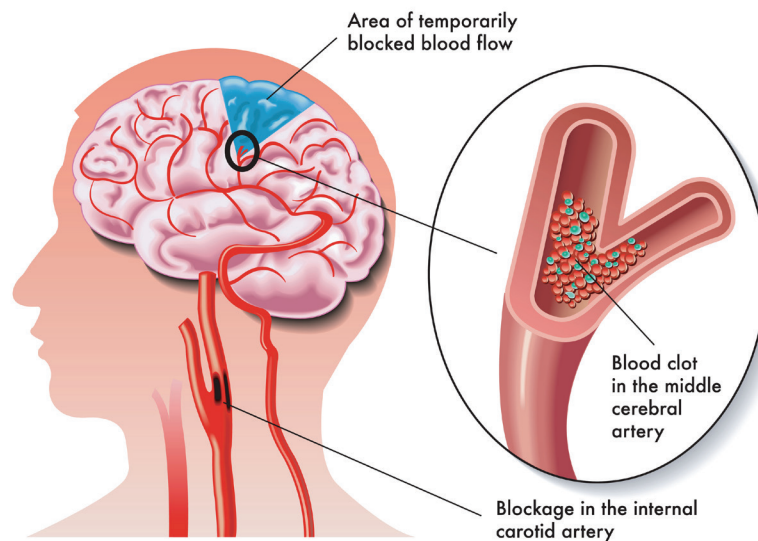
There Are 2 Types of Strokes

Ischemic: Occurs when a blood vessel is blocked.

Hemorrhagic: Occurs when a blood vessel bursts within the brain.



TIA (“Mini Stroke”): Caused by a temporary block. A TIA does not cause permanent damage, but is a **WARNING** sign that a stroke may occur.



“TIME IS BRAIN AT ANY AGE”

Perinatal & Childhood Stroke Basics

	PERINATAL (22 weeks pregnant - 1 month old)	CHILDHOOD (1 month to 18 years)	ADULT <i>(Since most people know more about strokes in adults, this category is for information only)</i>
TYPES	About 80% Ischemic 20% Cerebral Venous Sinus Thrombosis or Hemorrhage ^{10,8}	About 50% Ischemic 50% Hemorrhagic ¹³	About 87% Ischemic 13% Hemorrhagic ⁵
RISK FACTORS	<ul style="list-style-type: none"> In most cases, the cause is not known. Risk factors: Congenital heart disease Disorders of the placenta Blood clotting disorders Infections, like meningitis³ 	<ul style="list-style-type: none"> In many cases, the cause is not found. Risk factors: Congenital heart disease Disorders of brain vessels Infections Head injury Sickle cell disease Autoimmune disorders³ 	<ul style="list-style-type: none"> High blood pressure Atrial fibrillation Diabetes Smoking Atherosclerosis Obesity High cholesterol Family history⁴
WHAT TO LOOK FOR	<ul style="list-style-type: none"> Seizures: Rhythmic face, arm or leg twitching. Pauses in breathing along with staring episodes Hand preference: Before age one, the baby may only be using one hand or prefers using one hand over the other. Developmental Delays: As the baby grows, delays may be noticed. Decreased movement or weakness: usually on one side of the body 	<ul style="list-style-type: none"> Sudden numbness or weakness of the face, arm or leg (especially on one side of the body) Sudden confusion, difficulty talking or understanding Sudden trouble seeing (loss of vision or double vision) Sudden difficulty with walking, dizziness, loss of balance or coordination Sudden severe headache. Sudden headache with vomiting and sleepiness. New seizures (usually on one side of the body)³ 	<ul style="list-style-type: none"> Sudden numbness or weakness of the face, arm or leg on one side of the body Sudden confusion, difficulty talking or understanding Sudden trouble seeing (loss of vision or double vision) Sudden difficulty with walking, dizziness, loss of balance or coordination Sudden, severe headache with no known cause

Many times, we can't tell a parent why their child has a stroke. Here are some things that we do know:

General Facts

- Strokes do not discriminate. They can happen at any age.
- Strokes can happen in infants, toddlers, teenagers and adults. They can even happen in unborn babies.
- The actual rate of pediatric strokes is not known. According to Dr. Rebecca Ichord of The Children's Hospital of Philadelphia, "The U.S. does not have a system in place that can provide uniform, reliable reporting on the incidence of stroke in children, much less on the causes, treatment or outcome in children".⁹
- Of kids who survive a stroke, about 60% will have permanent neurologic deficits. These deficits may include (see 'Terms You Can Use' pg. 21-22 for more information):
 - Hemiplegia
 - Hemiparesis
 - Learning and memory problems
 - Difficulty with speech and language
 - Visual problems
 - Behavior or personality changes
 - Epilepsy
 - Swallowing and eating problems^{6,7}
- Boys are more likely to have a stroke than girls.⁷
- African American kids are at more risk as compared to White and Asian kids.⁷
- When a kid has a stroke, it impacts everyone involved (parents, siblings, grandparents, etc.).
- While the clot-busting drug tPA is a key for treatment of ischemic stroke in adults, it is not yet FDA approved for young children and infants.⁷
- Signs of stroke in babies may not be seen until developmental stages are missed.⁸

Perinatal Stroke Facts

- Perinatal strokes are often missed because the signs and symptoms are subtle. In most cases, a cause cannot be found.⁶
- When stroke occurs in an infant, signs may not be noticed for months to years.⁶
- For perinatal strokes, the overall risk for another stroke is very low, <1%.⁶
- The most common type of stroke in the perinatal period is ischemic stroke.⁸
- A stroke just before birth may also be called fetal, prenatal, or in-utero.
- A stroke just after birth may also be called neonatal or newborn.

Childhood Stroke Facts

- Childhood stroke may be missed because there is a lack of awareness that kids can have strokes. At first, stroke may even be diagnosed as something else.⁶
- Stroke happens as often as brain tumors in kids.⁶
- Stroke is one of the top ten causes of death in kids ages 1-19.⁷



“Put your kids in as many activities as you can...you never know what their interests will be. There are many sports that can be adapted to meet the needs of your child. Having my children in a lot of sports has helped them make a lot of friends and gain a lot of confidence in themselves.”

- Lori Malawski (Alex and Amanda's mom)

PERINATAL

(22 weeks of pregnancy-1 month)

- The most common type of stroke in perinatal period is ischemic stroke.⁸
- The time period just before birth may also be called fetal, prenatal or in-utero.
- The time just after birth may also be called neonatal or newborn.

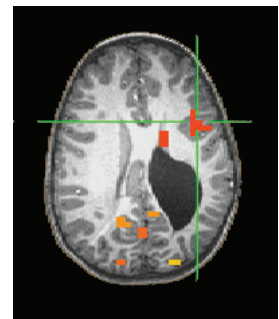
Signs & Symptoms

- Newborns may or may not show early signs of stroke.²
- The most common early sign is **seizures**. You may note:
 - Rhythmic twitching of the face, arm or leg.
 - Pauses in breathing along with staring.³
- Symptoms may also be noticed as the child develops:
 - Preference for using **one hand** over the other before age one.³
 - Decreased movement or weakness on one side of the body.³
 - Seizures²



Diagnosis

- Doctors may have used these tests to diagnose the stroke:
 - Head Computed Tomography (CT).
 - Magnetic Resonance Imaging (MRI).
 - May require medicine for sedation.
 - Ultrasound²
- Other tests may be done based on your child's signs and symptoms and type of stroke:
 - Electroencephalogram (EEG) is often done if seizures are present or suspected.
 - Electrocardiogram (ECG or EKG) may done if a heart problem is present or suspected.
 - Blood samples may be taken to check for blood clotting problem.²



Treatment

- Doctors may treat the baby at the time of the stroke with:
 - Medicines to control seizures, called anticonvulsants.¹⁰
 - Control body temperature, hydration and blood sugar.¹⁰
 - Manage brain pressure.¹⁰
 - Surgery may be needed for hemorrhagic stroke.¹¹



CHILDHOOD STROKE

(1 month - 18 years)

Signs & Symptoms

- **Sudden** numbness or weakness of the face, arm or leg on one side of the body.
- **Sudden** confusion, difficulty talking or understanding.
- **Sudden** trouble seeing (loss of vision or double vision).
- **Sudden** difficulty with walking, dizziness, loss of balance or coordination.
- **Sudden** severe headache (especially with vomiting and sleepiness).
- New **seizures** (usually on one side of the body).³

Diagnosis

- Doctors may have used these tests to diagnose the stroke:
 - Magnetic Resonance Imaging (MRI).²
 - Head Computed Tomography (CT).
- Other tests may be done based on your child's signs and symptoms and type of stroke:
 - Electroencephalogram (EEG) is often done if seizures are present or suspected.
 - Electrocardiogram (ECG or EKG) may be done if a heart problem is present or suspected.
 - Blood samples may be taken to check for blood clotting problem.²

Treatment

Know the Signs of Stroke and Call 9-1-1

- Doctors may treat the child at the time of the stroke with:
 - Medicines to control seizures, called anticonvulsants.¹⁰
 - Control body temperature, hydration and blood sugar.¹⁰
 - Control high blood pressure with medicines if needed.
 - Manage brain pressure.¹⁰
 - Surgery may be needed for hemorrhagic stroke.¹¹
 - Blood transfusion may be needed for Sickle Cell Disease.¹¹
- Medicines to prevent a second stroke, such as blood thinners, may be recommended by your doctor. This will depend on the cause of your child's stroke.¹⁰



“Never be afraid of a diagnosis your child receives; all it does is open him or her up for additional services that will help”

- Alisa (Jackson's mom)

Beyond: A Therapy Roadmap

Infants and Toddlers (Ages 1 month to 3 years)

Rehabilitation is key to help with long term outcome.

As the child grows, their needs for therapy and services may change. This section will serve as a roadmap to therapies and services that your child may need as they grow up.



“Make daily stretches/exercises a part of your child’s every day routine starting at a young age. You may not have as much resistance when they get to be teens.” - Mary Kay (Michelle’s mom)

- **Physical Therapy in this age group will include:**
 - Focus is on gross motor skills: sitting, crawling, walking, jumping, and running.
 - Strengthening exercises to help with muscle tone.
 - Increase movement.
 - Balance
 - Special splints and braces.
 - E-Stim (a therapy that can help improve muscle function).
 - Making an exercise plan for home.¹²
- **Occupational Therapy in this age group will include:**
 - Focus is on fine motor skills: holding a cup, coloring with a crayon, using a fork and spoon, picking up cereal, using both hands to grab toys.
 - They help children in learning, playing, and growing.¹²
- **Speech Therapy in this age group will include:**
 - Focus is on speech development and eating and swallowing.
 - Infants will be evaluated for appropriate suck-swallow coordination.
 - Toddlers will be evaluated for speech development.
 - Some toddlers will learn sign language until they can effectively communicate verbally.
 - Often children that have suffered a stroke understand what you are saying to them, but are unable to verbally express themselves.¹²



Early Childhood (Ages 4 years to 12 years)

- **Physical Therapy will focus on gross motor skills like walking and running.**
 - Strengthening exercises to help with muscle tone
 - Increase movement
 - Balance
 - Gait training
 - Special splints and brace
 - E-Stim (a therapy that can help improve muscle function)
 - Constraint Induced Movement Therapy (CIMT)
 - During this therapy, the unaffected arm/hand is restrained, so that the child is encouraged to use the affected arm/hand. In some children, this has proven to be an effective treatment.
 - Making an exercise plan for home¹²
- **Occupational Therapy will focus on fine motor skills.**
 - Eating independently
 - Dressing independently
 - Promote self-hygiene such as: bathing, going to the bathroom, brushing teeth, brushing hair, etc.¹²
- **Speech Therapy will focus on swallow coordination, speech, language and cognition.¹²**
 - Swallow study may be performed to assess for any problems.
 - Effective communication
 - Memory, recall, and attention will be assessed.
- **An evaluation by a neuropsychologist may be helpful at this stage.**



Teenagers (Ages 13 to 18 years)

- **Physical Therapy will focus on gross motor skills like walking and running.**
 - Strengthening exercises to help with muscle tone
 - Increase movement
 - Balance
 - Gait training
 - Special splints and brace
 - E-Stim (a therapy that can help improve muscle function)
 - Constraint Induced Movement Therapy (CIMT)
 - Making an exercise plan for home¹²
- **Occupational Therapy will focus on fine motor skills.**
 - Eating independently
 - Dressing independently
 - Promote self-hygiene such as: bathing, going to the bathroom, brushing teeth, brushing hair, etc.¹²
- **Speech Therapy will focus on swallow coordination, speech, language and cognition.¹²**
 - Swallow study may be performed to assess for any problems.
 - Effective communication
 - Memory, recall, and attention will be assessed.



Beyond: Resources for Both Inside & Outside the Hospital

People and Places You May Need

As the child grows, their needs for therapy and services may change. This section will review some of the people and places that your child may need both inside and outside of the hospital.

- **Pediatrician:** a community-based general health specialist for kids. Can help to coordinate issues with child's general health.
- **Rehabilitation Specialists:** includes doctors such as physiatrists and developmental pediatricians with expertise in child rehabilitation.
- **Neuropsychologist:** a person who can assess and help with learning and education needs.
- **Psychologist:** a person who can help with the stresses in both child and family that are common in stroke.
- **Orthopedic surgeon:** a doctor who is an expert in the "mechanical" complications of stroke such as tightness in an arm/leg or issues with limb length, that may be helped by surgery.
- **Hematologist:** a person who can help with testing and treatment of blood clotting disorders or occasional rare causes of stroke in children.
- **Neonatologist:** a doctor who is an expert in newborn care.
- **Neurologist:** a doctor who specializes in disorders of the brain.
- **Neurosurgeon:** a doctor who specializes in surgery of the brain. A neurosurgeon may occasionally be involved with certain types of stroke that require surgery.
- **Case Manager:** a person who will coordinate your child's discharge from the hospital. This person can help to make sure that your family is connected with resources for continued recovery after you leave the hospital. Your case manager will speak regularly with your child's doctors, and therapists to check on progress and help to determine what services he/she may need. You can expect to meet with your child's case manager soon after you arrive to the hospital to start to talk about discharge planning, even if you think your child's stay at the hospital may be lengthy.



- **Pediatric Acute Inpatient Rehabilitation (AIR)** – Pediatric AIR is a place for children that need more therapy that can be provided at home or in an outpatient setting. It is like a hospital that can provide 3-4 hours of therapy each day for your child. If your child is eligible, a case manager will work with you to determine which AIR near you your child may be discharged to. Your child will be discharged directly to AIR and may stay there anywhere from a few days to several weeks.
- **Home Health Therapy/Nursing** – If your child is unable to leave home for therapy or nursing services, home health will meet with you and your child in your home to work on therapy goals and provide nursing teaching to you and/or other caregivers. Your child will transition to outpatient services once medically able.
- **Outpatient Therapy** – At some point, your child will likely benefit from outpatient therapy. Outpatient therapy is generally more rigorous than home health therapy and can be a long term treatment option.
- **Waiver Programs** – These programs provide services to children with extensive needs. Services vary from state to state and can range from in-home nursing or nurse aide services to parent education, case management and funding for home and vehicle modifications to make things more accessible to your child. If eligible, your child might also qualify for Medicaid, even if your family income is over the income limits. This program can have a long eligibility process, but your case manager can help you with starting the process.
- **Social Supplementary Income (SSI)** – SSI provides funding to assist your family in caring for your child with special needs. If your child has a disability that is expected to last for at least a year and your family meets certain income guidelines, your child may be eligible for SSI through the Social Security Administration.
- **Medical Equipment** – Your child may benefit from medical equipment to assist with mobility and activities of daily living (bathing, eating, etc.).
- **Educational Services** – Services for babies through school age children with disabilities are available in each state in the U.S. Every state has at least one Parent Training and Information Center (PTI) that you can contact for more information. Details about your state can be found on The Center for Parent Information and Resources website (www.parentcenterhub.org) under ‘Find Your Parent Center’.

WHAT SHOULD I ASK?

What type of stroke did my child have? Do you know why my child had a stroke?

Is my child at risk for seizures? What are the signs of seizures? What should I do if my child has a seizure?

Are there things that I need to do to prevent another stroke?

Does my child need therapy now and in the future?

Will my child need to be on medications after the stroke diagnosis?

What should I look for when I get home to warn me that something may be wrong?

Will my child be able to return to school? If yes, when? What does the school need to know?

Will my child need an Individualized Education Plan (IEP) or 504 Plan to help them with physical or learning changes?

PREPARING TO GO HOME



Who is my Primary doctor? _____

Who are my other doctors? _____

Phone numbers: _____

Who is my Social worker/Case manager? _____

Phone number: _____

What types of therapies/rehab treatment may my child need?

Physical Therapist: _____

Phone Number: _____

Location: _____

How often: _____

Occupational Therapist: _____

Phone Number: _____

Location: _____

How often: _____

Speech Therapist: _____

Phone Number: _____

Location: _____

How often: _____

Home Health Company: _____

Phone Number: _____

DME (Durable Medical Equipment) needed:

PAGES OF HOPE:

Throughout your journey, you may find yourself looking for resources often. Below, you will find some reliable websites that you can turn to. Remember that, as a caregiver, support for yourself is just as important as caring for your child. Information on self-care, mental health and support groups can also be found on these websites:

The International Alliance for Pediatric Stroke (IAPS)

www.iapediatricstroke.org

The *International Alliance for Pediatric Stroke* (IAPS) was created to unite pediatric stroke communities around the world to advance knowledge, awareness and research for pediatric stroke. IAPS provides information, inspiration, resources and the connection between families, medical specialists, researchers, healthcare providers and anyone affected by pediatric stroke. Through our website, awareness projects, outreach and education, you will find what you need to better understand how strokes impact infants, children and unborn babies.

The American Stroke Association

www.strokeassociation.org

The American Stroke Association serves consumers (stroke survivors, caregivers, and family and friends of those affected by stroke), healthcare professionals, organizations, hospitals and all Americans interested in receiving information about stroke.

The National Stroke Association

www.stroke.org

The National Stroke Association provides stroke education and programs to stroke survivors, caregivers, and healthcare professionals.

These resources were created by parents and families affected by pediatric stroke:

www.bellaflies.org

www.brendonssmile.org

www.fightthestroke.org

www.pediatricstrokewarriors.org



WORDS OF HOPE: ADVICE FROM PARENTS & CHILDREN



“You are fierce. You’re a survivor. You’re a fighter through and through. Little brave, breathe...There’s a mighty warrior within you. Our children are an inspiration, they are much more than a diagnosis, and they will continue to teach us all that differences can be beautiful and to never underestimate what they can overcome.”

- Kaysee (Addison’s mom)

“Try not to over-protect your child, encourage them to try new things. Let them see what they are capable of accomplishing.”

- Michelle (age 17, perinatal stroke survivor)



“Set your kiddo up for success. Always give them the tools that they need to succeed and become the best person they can be. Don’t set limitations as that can hold them back!”

- Dyan (Nathan’s mom)

“Statistics in medicine often tell you what your son won’t be able to do, they never tell you what he’ll be able to reach, thanks to love and science. Our son Mario, taught us to consider what we have as a gift and what we miss as an opportunity. When our son started to look at us deeply in our eyes, we understood that if we wanted the best from him, we should give him the best of us.”

- Francesca Fedeli (Mario’s mom)





Ankle Foot Orthotic (AFO)- a brace that is worn on the lower leg and foot. It supports the ankle and holds the foot and ankle in the right position. It also helps with stability.²

Arterial Ischemic Stroke (AIS)- Damage to the brain that is caused by blocked blood flow.¹⁰

Arteriovenous Malformation (AVM)- An abnormal connection of arteries and veins in the brain. This can cause hemorrhagic stroke.¹¹

Botox- Also called Botulinum toxin type A. It is a therapeutic muscle-relaxing medicine. It reduces the stiffness of muscles. It can also be used to help muscle spasms.²

Cerebral Sinovenous Thrombosis (CSVT)- A clot in a vein blocks drainage of blood from the brain. This can cause a stroke.¹⁴

Cerebral Palsy (CP)- Difficulty with physical movement that results from an abnormality or injury to the brain before or around the time of birth. Medical professionals may describe a perinatal stroke survivor using the term 'Cerebral Palsy'. Stroke can be a cause of CP.⁶

Childhood Stroke- A category of stroke that includes ages 31 days old to 18 years old.³

Computed Tomography (CT)- A study that uses x-rays that can help to diagnose stroke.¹¹



Constraint-Induced Movement Therapy (CIMT)- A therapy that promotes hand and arm function by using gentle restraint. In most cases, a cast or split is used on the stronger side to help promote better function on the affected side.²

Durable Medical Equipment (DME)- any equipment that provides therapeutic benefits to a patient in need because of certain medical conditions and/or illnesses. Examples include: Braces, wheelchair, walker etc.¹⁷

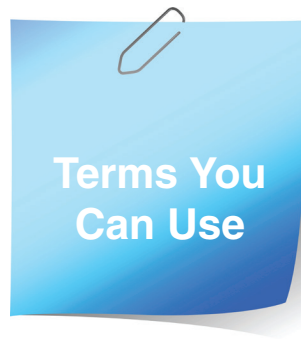
Dynamic Ankle Foot Orthotic (DAFO)- a brace that is worn on the lower leg and foot. It supports the ankle. It holds the foot and ankle in place and promotes stability.¹⁸

Electrocardiogram (ECG/EKG)- a non-invasive test that records the electrical activity of the heart and can show if there is a heart condition present.¹⁹

Electroencephalogram (EEG)- a study used to measure the electrical activity of the brain. It can assist in diagnosing seizures.¹⁹

Electrical Stimulation (E-Stim)-therapy that delivers an electrical current to stimulate nerves and muscles. This can help to improve muscle function.²⁷

Epilepsy (pediatric) – A seizure disorder. Seizures are sudden electrical problems in the brain. Stroke may be one cause of epilepsy.²¹



Expressive Aphasia- A type of language difficulty. In this type of aphasia, the child has difficulty putting words together and forming sentences. It may also be called 'Broca's Aphasia'.²⁰

Feldenkrais Method- supportive therapy that uses strategies to improve posture, flexibility, coordination, and to assist those with restricted movement.¹⁵

Fetal Stroke- subgroup of perinatal stroke that includes the time before birth. Also called "prenatal" or "in-utero".¹⁶

Hemiparesis- weakness on one side of the body.¹¹

Hemiplegia- paralysis on one side of the body.¹¹

Hemorrhagic Stroke (HS)- occurs when a weakened blood vessel ruptures.¹¹

Knee Ankle Foot Orthotic (KAFO)- a brace that goes from the thigh to the foot. It keeps the knee, ankle, and foot in position and promotes stability.²²

Magnetic Resonance Arteriography (MRA)- a non-invasive test that is used to visualize arteries and their blood flow.¹¹

Magnetic Resonance Imaging (MRI)- a test that uses a magnet and can help to diagnose a stroke.¹¹

Magnetic Resonance Venography- a non-invasive test that is used to visualize veins and their blood flow.¹¹



Neonatal Stroke- subgroup of perinatal stroke that includes time from birth to 1 month (30 days) old. Also called newborn.¹⁶

Plasticity- The brain's ability to reorganize connections and pathways.

Receptive Aphasia- A type of language difficulty. In this type of aphasia, the child has problems with understanding language. It is also called 'Wernicke's Aphasia'.²⁰

Supra Malleolar Orthosis (SMO)- a brace that supports the leg just above the ankle. It is the shortest of the braces. It helps to keep the heel in position²³

Transcranial Magnetic Stimulation (TMS)- A non-invasive tool that may be used to help with motor function. TMS uses a magnetic field that stimulates areas of the brain.²⁴

Transient Ischemic Attack (TIA)- A temporary block of blood flow that causes stroke-like symptoms. It does not cause permanent damage. It may also be called a "mini-stroke".¹¹

UCB- A foot arch support named after the place (University of California Berkley Laboratories) that made the first one.²⁵

Ultrasound- An ultrasound uses sound waves to show pictures of the brain, and blood vessels. Head ultrasounds are normally done on babies less than 6 months old. ²⁶

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