

Pediatric Stroke Family Tool Kit



International Alliance
for Pediatric Stroke
iapediatricstroke.org



A MESSAGE TO PARENTS

*We know that when you dreamt of becoming a parent, you never thought that your child could be impacted by a stroke. Oftentimes, our first experience with pediatric stroke is when our own child has received this diagnosis. When you are faced with the unimaginable, your initial reactions and feelings can become entirely overwhelming. Guilt, anger, sadness, fear, loneliness are all the most common feelings parents have shared. These feelings will demand to be felt at one time or another. **Be gentle with yourself. Acceptance is not an easy process. Fear of your child's unknown future can be very overwhelming.***

*Creating an army of advocates not only for your child's care but also for your family, is vital in this process. We simply cannot stress the importance of support enough. It can come from sources you may not have expected. Your child's doctors and therapists can often become an extension of your family. While you adjust to the ongoing medical appointments and therapies your child will need, keep in mind these medical professionals care about your child and their success. As you become familiar with them, continue to build those relationships and conversations over your child's care. **You are not just a bystander in this. You will learn how to advocate for your child and their needs.***

*We encourage you to gain as much knowledge about the resources and support available to your family. **The Pediatric Stroke Family Tool Kit** is intended to give families guidance on how to navigate this journey after their child has suffered a stroke. Our leadership team of dedicated parents and professionals worked together to bring a comprehensive resource about pediatric stroke into the hands of those that need it most — families. It is our hope to empower you and share with you knowledge that will help you ask some of those important questions, advocate for your child's best care, and fill your family with strength. We want you to know that **you are not alone.***

You may not be ready to read these pages or desire to learn more just yet, and that's ok! Take the time that you need to process. When you are ready, ask questions and seek support.

Sincerely,

*Kaysee Hyatt
Former Founder/Executive Director of Pediatric Stroke Warriors and
original author of this Tool Kit*

*Mary Kay Ballasiotes
Founder/Executive Director of International Alliance for Pediatric Stroke*

ACKNOWLEDGEMENTS

The original Pediatric Stroke Warriors Tool Kit was developed and created by Kaysee Hyatt, founder and executive director of Pediatric Stroke Warriors (PSW) in 2017. When PSW closed their doors in July 2020, the *International Alliance for Pediatric Stroke (IAPS)* was asked to carry the tool kit forward. We have made updates with the help of medical specialists. IAPS sincerely thanks Kaysee and PSW for all their work supporting families impacted by pediatric stroke.

CONNECT WITH US — **INTERNATIONAL ALLIANCE FOR PEDIATRIC STROKE**

EMAIL - info@iapediatricstroke.org

WEBSITE - iapediatricstroke.org

INSTAGRAM - [stroke.pediatric](https://www.instagram.com/stroke.pediatric)

FACEBOOK - [InternationalAlliance
forPediatricStroke](https://www.facebook.com/InternationalAllianceforPediatricStroke)

X (TWITTER) - [@StrokePediatric](https://twitter.com/StrokePediatric)

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PARENT TO PARENT – TAKING CARE OF YOU

In order to care for our children, we must make it a priority to take care of ourselves as well. This is often easier said than done. From the voice of parents who have been there, make it a point to put these shared words of advice into practice.

It's ok to ask for help. Acknowledging you need help balancing it all can be just as difficult as accepting it. Your family and friends often want to help you and giving that help lets them feel like they are supporting you during this stressful time. Make a list of things that need to be done to keep your life running, and be realistic about what you have the time and energy to accomplish. Keep the list handy, and the next time a friend or family member asks, let them know what they could do to help.

Recharge your batteries once in a while. Taking a break helps you be a better parent, partner, and person. You do not need to have all the answers or be “on” every second. We know it is scary to leave your child’s side, but you do really need to get away — even for a little while. Make plans for a friend or family member to spend time with your child while you spend time away. Read a book, go shopping, have a meal at a restaurant, nap — just be sure to relax!

Build a village of support. Being the caregiver of a child with medical needs can be an isolating experience. Whether friends and family, parent to parent support groups, or your child’s medical team — it is important that you reach out and connect with others who can help you feel less alone in this journey.

Distraction, Distraction, Distraction. Keeping up with favorite hobbies or developing a new one is a good way to take a mental vacation. Gardening, golfing, reading, drawing, blogging are all easy ways to busy your hands and quiet your mind.

Take care of yourself. When you are caring for your child, your health becomes secondary. However, if you aren’t healthy, meeting your child’s needs will be more difficult. Find time to exercise, even if you are just taking a walk. Pay attention to your emotional state and contact your doctor if you are concerned about anxiety or depression. Do not be ashamed to admit when you may need support.

Knowledge is power. Learn about your child’s diagnosis, medication, and treatment plan. (Be sure to ask your doctor for reputable websites ONLY). Keep a notebook nearby and write down questions as you think of them to address later with your child’s care team. You are the most important part of the team!

Educate others. Knowledge is power to family and friends as well. Ask them to take the initiative in learning more about your child’s diagnosis. This becomes especially important if your child has risk measures to avoid or has seizures. All family and friends who care for your child must understand these risks and how to respond.

Take back your family. Don’t let your child’s diagnosis define them or your family. Of course recovery takes precedence, but it’s important to recognize that your child’s recovery places all members of the family under stress and makes it more difficult for you to support each other. This is especially true for siblings in the family who may have thoughts or fears that they aren’t sharing. Make it a point to spend time together as a family in ways your family can all enjoy.



Lelaina Jaymes “Laney” Fitzsimons
8/19/2012—3/27/2017

In memory of Lelaina Jaymes “Laney” Fitzsimons, a happy, healthy 3-year-old who suffered multiple, misdiagnosed strokes over a 2-week period. She continued to have multiple massive strokes over the next 10 months. Unfortunately, the damage to her brain was too much. Laney passed away at home at age 4, surrounded by the love and affection of her family. Laney taught us all so much about love, perseverance, strength, kindness, and to never take things for granted.

The Laney Jaymes Foundation, laneyjaymes.org

DISCLAIMER

Please note that the Pediatric Stroke Family Tool Kit is for educational purposes only. The content is not intended to be a substitute for professional medical advice, diagnosis, treatment, or for legal advice or representation, nor is it intended to be interpreted as such. Please seek out a medical or legal professional for those types of services/advice.

International Alliance for Pediatric Stroke provides general information about Pediatric Stroke as a service to communities. The following information provided in this tool kit is not a referral or endorsement of any resource, therapeutic method, or medical service provider, and does not replace the advice of any medical professional.

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CONTENTS

ABOUT PEDIATRIC STROKE

Strokes at a Glance	6
Types of Stroke	7
Perinatal Stroke	8
Childhood Stroke	9
Diagnosis.....	10
Hospitalization	11

AFTER STROKE

The Care Team.....	12
Important Questions.....	13
Starting the Path Forward	14
Therapies Overview	15

THE PATH FORWARD

Birth to Three	17
Transition to Preschool	19
Early Childhood (Ages 4—12).....	20
Teens (Ages 13—18).....	22
Important Questions	24
Ongoing Care: Rehab & CIMT.....	25
Bracing & Orthotics	26
Creating a Care Notebook	27

RESOURCES AND SUPPORT

Support Groups	28
Organizations.....	29
Special Needs Resources	30
Books & Publications.....	30
Financial Assistance Resources	31

WORDS FROM THE HEART

The Heart of a Mom	32
The Heart of a Survivor.....	34

GLOSSARY OF MEDICAL TERMS

Common Medical Professionals.....	37
Commonly Used Medical Terms	38

REFERENCES	42
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QUICK GLANCE AT THE FACTS

- Delays in diagnosis are common in both perinatal and childhood stroke, but for different reasons.¹
- Seizures at stroke onset are more common in children than adults.¹
- Stroke is among the top 12 causes of death between the ages of one and 19.²
- Of children surviving stroke, about 60% will have permanent neurological deficits, most commonly hemiparesis or hemiplegia. Hemiplegia is the most common form of cerebral palsy in children born at term, and stroke is its leading cause.²
- Other long-term disabilities caused by a stroke in childhood can include cognitive and sensory impairments, epilepsy, speech or communication disorder, visual disturbances, poor attention, and behavioral problems.²



WHAT IS STROKE?

Stroke happens when blood that carries oxygen and nutrients stops flowing to part of the brain. Without a steady supply of blood, brain cells in the area begin to die within seconds. This can lead to stroke symptoms and sometimes to lasting neurologic deficits or sadly, death.

While most have heard of stroke in adults, a stroke can and does happen at any age. Stroke can happen before birth, in newborns, children, and teens. Stroke in children is often different from adult stroke, with different causes and sometimes different symptoms and treatments. In babies and children, epilepsy, tumors, migraine headache, and many other conditions can mimic stroke. Careful, expert diagnosis is essential to tell pediatric stroke from other health problems so your child gets the right treatment.

A stroke is a medical emergency. If you think a child is having a stroke, call 9-1-1. A rapid response, quick diagnosis and treatment for a child may help limit damage to the brain.

CATEGORIES FOR PEDIATRIC STROKE

There are two age categories when referring to pediatric stroke:

- **Perinatal**, which refers to 28 weeks' gestation through the first 28 days after birth. It is also called **Neonatal** stroke.¹
- **Childhood**, which refers to ages 28 days to 18 years.¹



TYPES OF STROKE

ISCHEMIC STROKE (pronounced iss-KEE-mik)

In ischemic stroke, a blood vessel in the brain is blocked. Blood cannot get through the vessel to deliver oxygen and nutrients to the cells that need it. The blockage may be from a blood clot that formed in the blood vessel (thrombus) or a clot that formed somewhere else in the body, such as the heart, and then traveled to the brain through the bloodstream (embolism).

Doctors group pediatric ischemic strokes by the age of the child.

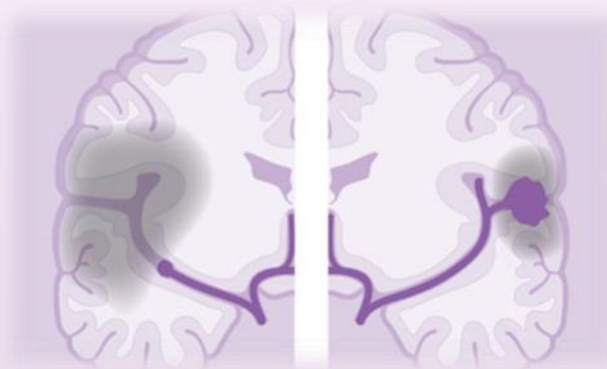
- Perinatal ischemic stroke (PIS): Stroke before birth or in a newborn (age 28 days or younger).
- Childhood arterial ischemic stroke (childhood AIS or CAIS): Stroke at age 29 days or older.

HEMORRHAGIC STROKE (pronounced hem-or-ADJ-ik)

In hemorrhagic stroke, a blood vessel in the brain is bleeding. Blood is leaking from the vessel before it can get to the cells that need oxygen and nutrients. The lack of oxygen-rich, nutrient-rich blood to brain cells is only one problem. Another problem is that blood builds up where it does not belong — in the brain, but outside a blood vessel. This blood can put pressure on the brain, form clots, or cause nearby blood vessels to close up (vasospasm), which can also damage the brain.

Causes of hemorrhagic stroke include:

- Weak blood vessel bursting
- Trauma, such as a head injury, that tears the wall of a blood vessel



CEREBRAL SINOVENOUS THROMBOSIS (CSVT)

Cerebral sinovenous thrombosis is a rarer type of stroke in children. CSVT causes a blood clot in the veins within the brain. This type of stroke can stop blood and fluids draining from the brain, resulting in increased pressure or bleeding.¹¹

TRANSIENT ISCHEMIC ATTACK (TIA)

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

If the blockage clears, the blood supply starts and the signs disappear. Signs may be present for a few minutes. A TIA will have no lasting impact.¹¹

PERINATAL STROKE KEY POINTS

- The incidence rate of perinatal stroke is approximately 1 in 1,100 live births, according to some studies.⁵³
- The most common type of stroke in the perinatal period is ischemic stroke.¹
- After a perinatal stroke, the risk of another stroke is very low — less than 1%.⁵
- A stroke before birth may be called fetal, prenatal, or in-utero and a stroke just before birth may be called neonatal or newborn.
- Perinatal stroke is the most common cause of hemiplegic cerebral palsy.⁴
- In most cases of perinatal stroke, a cause cannot be determined.¹
- Perinatal strokes are often missed because the signs and symptoms are subtle. Many infants do not show any signs of stroke until they are 5 months or older.⁴
- Currently, there is no established immediate treatment for perinatal stroke.⁴
- Intervention during the first few years of life (while the brain has the most plasticity) could improve the outcome after perinatal stroke.⁴
- Infants with early hand preference before 12 months should see their pediatrician and request a referral to a pediatric neurologist to rule out anything neurological.⁵



PERINATAL STROKE SYMPTOMS

Symptoms of stroke tend to be different in newborns (age 28 days or younger) than in older children.

Signs and Symptoms in Newborns:

- Seizures (repetitive twitching of face, arm, or leg)
- Apnea (pause in breathing) associated with staring
- Lethargy, poor feeding⁵

WHAT TO DO:

Alert medical team/emergency services for possible signs of stroke.

Signs and Symptoms in Developing Babies:

- Decreased movement or weakness on one side of the body
- Hand preference before 1 year of age
- Developmental delays⁵

WHAT TO DO:

Consult with your child's health care team, which may include a pediatric neurologist. An MRI of the brain is usually required.

PERINATAL STROKE RISK FACTORS

- Disorders of the placenta
- Congenital heart disease
- Acute blood-clotting disorders
- Infections, such as meningitis⁵

It is very important for mothers to understand that there is often nothing they did or did not do during their pregnancy that led to their child's stroke.

CHILDHOOD STROKE KEY POINTS

- Childhood strokes may be missed because there is a lack of awareness that children can indeed have a stroke. Delays in seeking medical care, confirming diagnosis, and accessing an MRI can be 24 hours or more.¹
- Incidence rates vary, but the highest rate is in children under 5, and higher in boys than girls. Black and Asian children have a higher incidence than white children.¹
- Many children with stroke symptoms are misdiagnosed with the more common conditions that stroke can mimic such as migraines with aura, seizures, or Bell's Palsy.¹
- In older children, the signs and symptoms of stroke are very similar to those in adults and depend upon the area of the brain involved.¹
- The rate of recurrent strokes is about 12% by 1 year post stroke, mainly in children with diseases of the arteries.¹
- To date, the use of tPA (a clot-busting treatment) and thrombectomy (clot retrieval procedure) are not currently FDA approved for children in the U.S. These treatments have been used in some children, but more research is needed.³
- Early recognition and treatment during the first hours and days after a stroke is important to optimize outcome.



CHILDHOOD STROKE SYMPTOMS

As in adults, **F**ace drooping, **A**rm weakness, **S**peech difficulty, **T**ime to call 9-1-1 applies to children.

Additional warning signs in children:

- Sudden severe headache, especially with vomiting and sleepiness
- Sudden numbness or weakness on one side of the body (face, arm, and/or leg)
- Sudden confusion, difficulty speaking or understanding others
- Sudden trouble seeing in one or both eyes
- Sudden difficulty walking, dizziness, loss of balance or coordination
- New onset of seizures, usually on one side of the body³

WHAT TO DO:

If your child has one or more of these signs, DON'T DELAY — Call 9-1-1 or the emergency system!

If it looks or feels like a stroke, it may be one!

CHILDHOOD STROKE RISK FACTORS

In some cases of childhood stroke, a cause is never found. However, about half of the children presenting with a stroke have a previously identified risk factor.³

Medical conditions associated with stroke include:

- Congenital Heart Diseases
- Sickle Cell Disease
- Moyamoya Disease
- Abnormalities of arteries in the brain
- Autoimmune Disorders
- Blood Clotting Disorders³

STROKE DIAGNOSIS

To diagnose stroke, the doctor will examine your child and ask about your child's symptoms and health history. It is important to make sure these tests are explained to not only you, but also to your child in words they will understand. Describe the equipment, the sounds, and the environment they will experience. Make sure they know they will not be alone.

To see pictures of your child's brain and look for blockage, bleeding or problems with the blood vessels, the doctor may ask for your child to have one or more of these imaging studies:

- CT (computed tomography) scan
- MRI (magnetic resonance imaging) scan
- MRA (magnetic resonance angiography)
- Ultrasound
- Cerebral catheter

Your child may also have one or more of these tests performed:

- Blood tests to check for clotting or bleeding problems, infection or diseases that might increase stroke risk
- Echocardiogram to check for heart problems
- Electrocardiogram to check for problems with heart rate or rhythm
- Electroencephalogram to look for possible seizures

HOSPITAL TREATMENTS

Treatment for perinatal stroke and childhood stroke depends on:

- The type of stroke
- The short-term and long-term effects of the stroke
- Any underlying condition that caused the blockage or bleeding in your child's brain

Children who have had an acute stroke will be admitted to the hospital for further tests to determine the causes and impact of the stroke and to provide treatment.

- If a blood clot is blocking blood flow in your child's brain (ischemic stroke), doctors may use blood thinners (antithrombotics, either antiplatelets or anticoagulants) to keep clots from getting larger and to prevent new clots. The drug tPA is widely used in adults in the hours right after an ischemic stroke. However, doctors are still studying how it affects children and which children can benefit.
- If your child has an underlying condition that might have caused the stroke, and might put your child at risk for future strokes or other health problems, doctors may recommend treatment for this condition.
- Medicine to prevent a second stroke, such as blood thinners, may be recommended by your child's doctor. This will depend on the cause of your child's stroke.
- Rehabilitation including physical, occupational, and speech therapy is key to improve outcomes over the long-term.

HOSPITAL RECOVERY AND REHABILITATION FOR YOUR CHILD

A child's brain is still growing, developing, and constantly learning. Rehabilitation is key following stroke and can lead to significant improvements in the long-term outcome for your child. The length and type of rehabilitation needed will be different for all children.

Your child's rehabilitation team will collaborate and determine the types of therapy best suited to incorporate for your child's recovery. Parents and caregivers are an important part of this team and should be encouraged to ask questions and receive training on how to best support their child throughout recovery.

Important things to know during rehabilitation:

- Your child's rehabilitation plan will continue to change as progress is made. The medical team should work with your family to prepare for your child's return home. You may need to consider making modifications to your home to make it safe and accessible for your child.
- When you leave the hospital, rehabilitation should continue and may occur in different settings depending on your child's age and need. Programs can include an outpatient clinic, early intervention services, pediatric specialty clinics, and/or community programs in your area.
- Your child will continue to have appointments with their rehabilitation specialist to assess and follow up on their recovery. Every child's recovery from stroke is unique, and the medical team is there to make sure your child has the services they need in order to have the best recovery possible from their stroke.





ALISA – MOTHER TO JACKSON, PERINATAL STROKE WARRIOR

“Never be afraid of a diagnosis. It will only open your child up to more services. And don't be afraid to push back on any therapist or medical provider when you feel you are not getting the clear information you need. Always work as a team when it comes to your child. “

YOUR CHILD'S CARE TEAM

There will be a variety of different types of medical professionals involved in the care of your child while in hospital and after discharge. They should all work together as a team. Family members and patients are very important members of this team and should be active participants in care-planning and decision-making for their child.

Each of these medical professionals, at one time or another, may be involved in your child's care. Based on your child's specific needs, their medical team may include:

- Cardiologist
- Case Manager
- Developmental Pediatrician
- Epileptologist
- Genetic Counselor
- Hematologist
- Neonatologist
- Neuro-Ophthalmologist
- Neuropsychologist
- Neurosurgeon
- Occupational Therapist
- Orthotist
- Pediatric Neurologist
- Pediatric Ophthalmologist
- Pediatric Orthopedic Surgeons
- Physiatrist
- Physical Therapist
- Social Worker
- Speech-Language Pathologist

It is important to keep communication open and to continue asking your child's medical team questions throughout your child's care. Don't be afraid to ask multiple questions, and make sure you understand what is important to know. Write down questions before you meet with your medical team and then take notes on the answers.

AFTER STROKE: IMPORTANT QUESTIONS

What type of stroke did my child have, and do you know why my child had a stroke?

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

Is my child at risk for seizures and what signs should we be aware of?

What should I do if my child has a seizure?

What should I look for once my child is discharged from the hospital that may warn me something may be wrong?

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

Who should I contact if I have a concern or if I have further questions?

Is there a social worker or case manager who can guide us?



AFTER STROKE: STARTING THE PATH FORWARD

THE FAMILY'S ROLE IN RECOVERY

Parents and families have a primary role in their child's development. Your child's therapy team should collaborate with your family to promote development and to implement an individualized intervention program for your child based on age and areas of focus. Families should also address the questions on how to coordinate therapy in day-to-day living for their child.

REHABILITATION

Rehabilitation is key to help with long-term outcome. As the child grows, their needs for therapy and services may change.

Physical Therapy (PT) in all ages promotes independence, increases participation, facilitates motor function and development, improves strength and endurance, enhances learning opportunities, and eases challenges with daily caregiving.

Occupational Therapy (OT) will evaluate your child's ability to perform self-care, play, and school skills at an age-appropriate level. The goal of OT is for the child to participate as actively and fully as possible in all areas — self-care, play, and school skills.

Speech-Language Pathologists (SLP) evaluate communication skills and treat speech and language disorders.

UNDERSTAND YOUR INSURANCE

Private and public health insurance programs in the U.S. may cover payment for certain therapy, medications, and/or mobility equipment, but the services and reimbursement may vary greatly. Families should become familiar with the benefits provided by their policy or program in advance and keep track of all communications and statements of explanation.

AFTER STROKE: PHYSICAL THERAPY

Pediatric physical therapy (PT) in all ages promotes independence, increases participation, facilitates motor function and development, improves strength and endurance, enhances learning opportunities, and eases challenges with daily caregiving.

Physical therapists will use their expertise in movement and apply clinical reasoning through the process of examination, evaluation, diagnosis, and intervention. Physical therapy will address the child's general strength and their abilities in the areas of gross motor skills and mobility.

Pediatric physical therapy may include any of the following services as part of your child's plan of care:

- Developmental activities
- Movement and mobility
- Strengthening
- Motor learning
- Balance and coordination
- Recreation, play, and leisure
- Adaptation of daily care activities
- Tone management
- E-Stim (a form of therapy that can help improve muscle function)
- Use of assistive technology
- Posture, positioning, and lifting
- Orthotics, AFOs, SMOs

AFTER STROKE: OCCUPATIONAL THERAPY

Occupation refers to all of the “jobs” that make up our daily life, whether you are child or a young adult. **Occupational Therapists (OT)** will evaluate your child's ability to perform self-care, play, and school skills at an age-appropriate level. The goal of OT is for the child to participate as actively and fully as possible in all areas — self-care, play, and school skills.

Through a comprehensive evaluation the therapist can begin to identify issues that interfere with a child's performance. This may include problems with strength, abnormal muscle tone, eye-hand coordination, visual perceptual skills, and/or sensory processing skills.

Pediatric OT may include a variety of approaches in assessing and treating children, including neuro-developmental treatment (NDT), sensory processing, motor learning approaches, constraint therapy, kinesiotaping, sensory integrative (SI) therapy, vision related therapies, and feeding related therapy. Therapy is child directed and based on activities that are meaningful and purposeful to that specific child.

Your child's therapist may incorporate various tools and adaptive equipment to increase independence. Examples can include specialized feeding utensils, adaptive scissors, writing utensils, and hand splints. They may recommend and show a parent and child how to use adaptations to clothing such as zipper pulls, button hooks, and Velcro in order to allow a child to learn further independence in self-care.



AFTER STROKE: SPEECH THERAPY

Speech-Language Pathologists (SLP) evaluate communication skills and treat speech and language disorders. This can include both receptive and expressive language, auditory processing, memory, articulation, fluency, oral-motor development, and feeding skills. The speech pathologist may also screen a child's hearing and make a referral for further evaluation if needed.

BEST SPEECH APPS TO TRY

- Articulation Station Pro by Little Bee Speech
- Brainbean
- BubbleABC
- Fun & Functional by Smarty Ears
- Language Adventure
- Peekaboo Barn by Night & Day Studios, Inc
- Sounds At Home
- Speech4Good
- ToyBrush 3D by Croco Studio

Please Note: The use of apps in no way replaces receiving certified help from a therapist. These speech apps are suggestions to assist your child at home and to help reinforce skills already being practiced at therapy sessions.

Speech disorders include:

- **Articulation disorders:** difficulties producing sounds in syllables and/or saying words incorrectly to the point that listeners can't understand what's being said.
- **Fluency disorders:** such as stuttering, in which the flow of speech is interrupted by abnormal stoppages, repetitions (st-st-stuttering), or prolonging sounds and syllables (s-ss-s-stuttering).⁸
- **Resonance or voice disorders:** problems with the pitch, volume, or quality of the voice that distract listeners from what's being said. These types of disorders may also cause pain or discomfort for a child when speaking.
- **Dysphagia/oral feeding disorders:** difficulties with drooling, eating, and swallowing.

Language disorders can be either receptive or expressive:

- **Receptive disorders:** difficulties understanding or processing language.
- **Expressive disorders:** difficulty putting words together, a limit in vocabulary, or inability to use language in a socially appropriate way.

Strategies:

- **Language intervention activities:** The SLP will interact with a child by playing and talking, using pictures, books, objects, or ongoing events to stimulate language development. The therapist may also use repetition exercises to build speech and language skills.
- **Articulation therapy:** The SLP will model correct sounds and syllables for a child, often during play. The SLP will physically show the child how to make certain sounds, such as the "r" sound, and may demonstrate how to move the tongue correctly to produce specific sounds.
- **Oral-motor/feeding and swallowing therapy:** The SLP will use a variety of oral exercises — including facial massage and various tongue, lip, and jaw exercises - to strengthen the muscles of the mouth. The SLP also may work with different food textures and temperatures to increase a child's oral awareness during eating and swallowing.



THE PATH FORWARD – BIRTH TO THREE

EARLY INTERVENTION

Rehabilitation is key to help with long-term outcome. Early intervention is vital during this initial time after stroke because a child learns and develops at the fastest rate during these first few years of life. It's important not to miss out on this crucial part of your child's development. Treatment will encompass multiple therapies and pediatric subspecialists.

The most common rehabilitation services after stroke for children in this age group are: **Physical Therapy, Speech Therapy, and Occupational Therapy**. In the U.S., these services are mandated by a federal law called the **Individuals with Disabilities Education Act (IDEA)**. The law requires that all states provide **Early Intervention (EI)** services for any child who qualifies, with the goal of enhancing the development of infants and toddlers. Children who are considered "at risk" of developing a delay may also receive services.

Each state has their own name for their Early Intervention Program. Your child's medical specialists can put you in touch with the program in your community. Or you can find the main contact information from the Centers for Disease Control website:

[cdc.gov/ncbddd/actearly/parents/state-text.html](https://www.cdc.gov/ncbddd/actearly/parents/state-text.html)

WHAT TO EXPECT FROM AN EVALUATION

Your child needs to be evaluated to determine if he or she is eligible for early intervention services. This evaluation is at no cost to your family because it is funded by the state and federal government.

You will be asked to sign a consent form prior to the evaluation and share information about your child's development, health, and their medical history. You will be asked to provide information about your family's resources, priorities, and concerns. This detailed information is necessary to help the early intervention team develop a plan that meets the needs specific to your child and family.

One step at a time.

In the beginning, it can feel like simply breathing becomes hard work.

As you begin going through the motions of doctor appointments, evaluations, therapy, and all the encompassing medical moments in your child's early life, you will reach a place of courage and determination that you may have never known as a parent.

As parents, we believe we are our child's teacher, but often it is our child that teaches us the greatest life lessons.

THE PATH FORWARD – BIRTH TO THREE

A team of professionals will work with you to evaluate your child’s development in five areas:

- **Physical:** reaching for and grasping toys, crawling, walking, jumping
- **Cognitive:** catching activities, following simple directions, problem-solving
- **Social-Emotional:** making needs known, initiating games, starting to take turns
- **Communication:** vocalizing, babbling, using two- to three-word phrases
- **Adaptive:** holding a bottle, eating with fingers, getting dressed

Once your child has been tested and determined to be eligible for early intervention services, you will meet with your early intervention team to develop a plan of services, called the **Individualized Family Service Plan (IFSP)**. The IFSP contains goals, or outcomes, that you and other members of the team will identify based on your family’s concerns, priorities and resources. Services will be identified to help your child and family meet the IFSP outcomes and will continually be updated as growth and goals are met.

EXAMPLES OF EARLY INTERVENTION SERVICES

If your child has a disability or a developmental delay in one or more of the above developmental areas, then they will likely be eligible for early intervention services. A child may need more than one service. These services will be specifically tailored to your child’s individual needs and may include:

- Assistive technology devices and services
- Audiology
- Family training, counseling, and home visits
- Health services
- Medical services for diagnosis and evaluation
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination services
- Sign language and cued language services
- Social work services
- Speech-language pathology
- Transportation and related costs
- Vision services⁷

Every effort is made to provide services to all infants and toddlers who qualify, regardless of family income. Services cannot be denied to a child just because his or her family is not able to pay for them. Under IDEA, the following services must be provided at no cost to families: evaluations and assessments, the initial development and ongoing review of the IFSP, and service coordination.⁶



THE PATH FORWARD – TRANSITION FROM THREE TO PRESCHOOL

EARLY DEVELOPMENTAL PRESCHOOL AND THE IEP PROCESS

Early intervention services will come to an end on your child's third birthday. A transition meeting with your family care coordinator, your child's current therapy team, and a school district representative will be scheduled 6 months prior to your child's third birthday, allowing time for a transition plan to be put into place.

Services for preschool children (ages 3 through 5) will be discussed and are provided free of charge through your public school system, if your child qualifies. These services are made available through the **Individuals with Disabilities Education Act (IDEA)** - the same law that applied to Early Intervention Services.

This transition meeting is a time of review, planning, and new goal setting for your family and child. You will talk next steps and learn about the programs or services that may be available for your child and for their continued development. Special education services can include individualized, specially-designed instruction in academic, self help, communication, motor, vocational, and social skill areas.

Individual Education Programs (IEPs) are developed for your child's specific needs based on the results of formal and informal testing and observations. The question as to whether or not your child will qualify for early childhood special education services and/or whether or not that is the route you believe would be best for your family are often heavily weighted.

Personal emotions, intertwined with the responsibility of making the right choices for your child's future, can often result in a time of uncertainty. This can be exacerbated by a new education process that may seem overwhelming at first. You may feel as if you are starting over in building a new plan of therapy for your child. In retrospect, you are. However, it is so important to stop and appreciate just how far your child has already come!

At the preschool age, families may decide to pursue private clinic therapy, and seek school-based services at a later age. Some families may even choose both school-based services and private therapy to be used in conjunction. The reality is, family dynamics of your child's therapy may vary. The best choice is always the one that fits your own family and your child's ongoing needs the most.

The transition to Developmental Preschool can bring about big emotions not only for parents, but can become challenging for your child as well.

Families who choose to enroll their child in these services can help the transition process and preschool experience be more meaningful and productive.

By visiting the school and building relationships with the teachers and therapists, you and your child can feel more comfortable in what to expect from a developmental preschool program.

Greater success can be reached when both the school and family are working together toward the same goals.

THE PATH FORWARD – EARLY CHILDHOOD (AGE 4 TO 12 YEARS)

A team of professionals should work with you to evaluate your child’s development and address their needs and treatment options in the following areas:

Physical Therapy Focus — Gross Motor Skills

- Strengthening exercises to help muscle tone/spasticity
- Active and passive range of motion
- Posture, balance, transitional movement
- Ankle Foot Orthotics (AFOs)/Supra Malleolar Orthotics (SMOs) for feet, ankles, and knees
- Robotics and virtual reality
- Neuromuscular electrical stimulation
- Intensive therapy (increased frequency and duration for a few weeks)

Occupational Therapy Focus — Fine Motor Skills

- Self-care, such as eating, dressing independently, personal hygiene
- Using two hands together as well as separately during play, self-care
- Use of the Manual Ability Classification System to assess the need for support and adaptation⁴⁷
- Constraint Induced Movement Therapy (CIMT)
- Wrist and hand braces for positioning
- Neuromuscular electrical stimulation
- Strapping/Kinesiotape
- Intensive therapy (increased frequency and duration for a few weeks)

Speech/Feeding

- Swallow study may be needed to assess any problems
- Evaluation for specific disorders
- Aphasia — affects a person's ability to express and understand written and spoken language
- Apraxia of Speech (Verbal Dyspraxia) — a speech disorder characterized by inability to speak, or a severe struggle to speak clearly
- Dysarthria of Speech — due to paralysis, weakness, improper muscle tone or incoordination of the muscles of the mouth⁵⁰

Cognitive (Neuropsychologist)

- Evaluate attention, memory, executive functioning, perception, language
- Pretend play and developmental play skills

Social-Emotional

- Self-regulation
- Ability to transition between tasks and places
- Behavioral changes

Vision (Neuro-Ophthalmologist)

- Visual perception
- Functional vision therapy to address visual field deficits
- Patching if needed for unilateral eye weakness



THE PATH FORWARD – EARLY CHILDHOOD (AGE 4 TO 12 YEARS)

EXAMPLES OF MEDICAL PROFESSIONALS FOR THIS AGE

- Neuro-Ophthalmologist
- Neurologist
- Neuropsychologist
- Occupational Therapist
- Orthotist
- Physiatrist
- Physical Therapist
- Speech Language Pathologist

EXAMPLES OF SCHOOL ACCOMMODATIONS

Under the **Individuals with Disabilities Education Act (IDEA)** and **Section 504 of the Rehabilitation Act of 1973**, there are accommodations that can help your child accomplish goals, participate, and make progress in school. Some to consider: ⁵²

- Use a marker to highlight important textbook sections
- Provide two sets of classroom curriculum materials/books, one for home and one for school
- Explore use of assistive technology (such as augmentative communication devices, computers, timers)
- Utilize a memory notebook
- Provide accessible classroom locations and accessible furniture (special desks, tables, chairs)
- Use both oral and printed directions
- Provide additional time to complete a task/tests
- Provide adaptive writing tools, pencil grips, slanted surface
- Reduce the amount of written work required
- Consider the child's fatigue level and need for rest breaks
- Pair student with other students modeling good behavior for classwork, projects, and mentoring

One day at a time.

Be supportive of the emotional and social adjustments your child will go through during these years. Consider seeing mental health professionals for your child and yourself.

Try to find a balance between therapy, needed medical appointments, and letting your child socialize and participate in extra-curricular activities.

Finding other families, either locally or online, who understand what you are going through, can help you through this difficult period.

THE PATH FORWARD – TEENS (AGE 13 TO 18 YEARS)

The team of professionals is expanded and should work with you to evaluate your teen's development and address their needs and treatment options in the following areas:

Physical (Beyond Physical Therapy and Occupational Therapy)

- Physical fitness, personal training
- Self-care during functional activities such as sports, moving through space at home or school or work
- Task-specific therapy to address balance, posture, and core strength such as: treadmill, exercise bike, adaptive bike, recumbent bike, weight bearing, aquatic therapy, strength and balance training
- Robotics and virtual reality
- Neuromuscular electrical stimulation
- Occupational Therapy assessment for Dyspraxia (difficulty in planning and carrying out skilled non-habitual motor acts in the correct sequence)⁴⁸
- Botox, spasticity treatment
- Ankle Foot Orthotics (AFOs) for gait

Communication (Speech-Language Pathologist)

- Speech therapy focusing on specific disorders
- Aphasia — affects a person's ability to express and understand written and spoken language
- Apraxia of Speech (Verbal Dyspraxia) — a speech disorder characterized by inability to speak, or a severe struggle to speak clearly
- Dysarthria of Speech — due to paralysis, weakness, improper muscle tone or incoordination of the muscles of the mouth⁵⁰

Cognitive (Neuropsychologist, Psychologist, Psychiatrist, Neurologist)

- The effects of stroke vary from person to person based on the type, severity, location, and number of strokes. Medical professionals can evaluate overall intelligence, verbal ability, working memory, and processing speed and offer ways to improve outcome.¹
- Difficulties with poor attention, impulsivity, and executive function¹
- Evaluate ability for self-care: for example cooking, daily living skills, problem solving

Social-Emotional (Mental Health Counselors/Clinicians/Therapists)

- Emotional disorders
- Behavioral issues
- Screenings for depression

Adaptive (Speech Language Pathologist, Occupational Therapist, Psychologist)

- School performance
- Community integration
- Quality of life
- Age-appropriate daily living skills



Whether the child has a perinatal or childhood stroke, this age must take into account the psychological and development areas that are most relevant and meaningful to the teen.

Driving and independence may be discussed during these years. Check with your local hospital for driving evaluations through the therapy clinics. Each state has different requirements so check with your state's Department of Motor Vehicles (DMV). There are auto accommodations that can be used to modify cars.

Transition to adulthood services planning starts at age 16 in the U.S. Utilize the IEP transition team in your school district to find the best path for your teen.

THE PATH FORWARD – TEENS (AGE 13 TO 18 YEARS)

EXAMPLES OF MEDICAL PROFESSIONALS FOR THIS AGE

- Mental Health Counselors/Clinicians/Therapists
- Neurologist — Brain mapping, Transcranial Magnetic Stimulation, seizures, EEG, brain activity, EMG biofeedback
- Neuropsychologist
- Nutritional Therapist/Counselor
- Orthotist
- Physiatrist
- Primary Care Physician — consultation for medications and referrals
- Psychiatrist, Psychologist
- Therapists — Occupational, Physical, Speech-Language Pathologist

EXAMPLES OF SPECIAL EDUCATION SERVICES

Under the **Individuals with Disabilities Education Act (IDEA)** and **Section 504 of the Rehabilitation Act of 1973**, there are accommodations that can help your teen. Some to consider: ⁵²

- Provide two sets of classroom curriculum materials/books, one for home and one for school
- Use both oral and printed directions
- Provide assistance when moving between classrooms or around the building
- Allow student to leave classroom 2 - 3 minutes early to avoid crowded hallways
- Provide a “designated note taker”
- Allow test to be taken in a room with few distractions and allow extended time
- Have the student practice presenting in a small group before presenting to the class
- Allow the student to use technology to record or dictate answers
- Provide access to word processing applications or software, portable note taker, tablet, or similar device

THE PATH FORWARD: IMPORTANT QUESTIONS

How can I modify or adapt toys, feeding utensils, items for self-care?

What mobility options with equipment are needed and available?

What activities are safe for my child?

What lifestyle changes are needed to keep my child healthy?

What information should be provided to other members of the family, daycare, and/or my child's school on how to best support my child's needs?

Will my teen be able to drive and what modifications are available?

What effect might the stroke have on my child's development, and what rehabilitation programs are available in my community?

Does our local hospital have a pediatric stroke support group or resources within the community for support?

Will my child need an Individualized Education Plan (IEP) or 504 Plan to help with physical and learning changes? Who do we contact within the school district? Should I get a special education advocate?

ONGOING CARE: BENEFITS OF HIPPO THERAPY

“The term Hippotherapy is a form of physical, occupational and/or speech therapy in which a trained therapist uses the characteristic movements of a horse to provide motor and sensory input.”⁹

Therapeutic horseback riding has been around for years. Riding not only builds on self-confidence, but the physical benefits of riding for children with disabilities are huge.

Riding can assist by improving a child’s balance, strengthening the muscles, and improving a child’s overall coordination. It can also promote sensory and motor input and improve sensory processing and neurological function.



CONSTRAINT INDUCED MOVEMENT THERAPY (CIMT)

Constraint Induced Movement Therapy (CIMT) has been applied to adult stroke patients with some beneficial results. This therapy is thought to increase the neural connections in the area of the brain that controls the affected side. Because of the success in adults with strokes, this therapy is now being applied to children.

Pediatric CIMT is a motor therapy program for children with limited function in one of their arms. It is geared for children who are able to interact with others during one-on-one and group therapy with children in the same age range.

CIMT is often given in an intensive series of lessons over a 2 to 3 week period and will take place in a fun environment that motivates the child to use the affected side. The non-affected arm is put in a long arm cast. During this time, your child will do intensive training of the arm that has limited motor function. Therapists will help your child use the affected arm often, repeating the same motion over and over again, shaping the desired movement.

Research continues to show that this form of therapy can increase the awareness and quality of movement required for two-handed activities.

Talk to your therapist and medical specialists about the appropriate age for your child in order to participate in this form of therapy and if there is a program in your community. Based on insurance and diagnosis, coverage varies for this type of therapy so we encourage you to confirm with your insurance before you attempt scheduling.



FINDING THE PERFECT “FIT”

The struggle is most often finding the perfect shoe for your child to wear over their orthotic. Some may only need to wear an orthotic on one foot, thus making a difference in shoe sizes an increased challenge in purchasing shoes.

Recommended brands by parents:

- Nordstrom (if at least 2 sizes apart, will sell as one pair)
- Keeping Pace
- EasyUp Shoes
- Hatchbacks
- New Balance
- Stride Rite – Wide
- Plae – with XL Tabs
- Nike Flyease
- BILLY Footwear
- Zappos Adaptive (one pair- different sizes, AFO friendly)



INTRODUCTION TO BRACING & ORTHOTICS

When a child first receives a diagnosis and treatment plan it will most often include a recommendation for bracing or orthotic intervention. This usually proves to be a learning process for both the parents and the child.

It's natural for parents to question the need for bracing and the benefits it will serve. As you learn more about orthotics and their potential role in the life of your child, you will come to know that orthotics can be a valuable resource for improving overall physical health and emotional well-being.

The Benefits of an Orthotic

Ankle Foot Orthotics (AFO'S) are commonly prescribed in children with neurological disorders such as stroke and Cerebral Palsy. Simply put, an AFO (sometimes called a brace or splint) provides support to help a child maintain a foot/ankle position, encourage mobility, and improve overall stability and success.¹⁰

Helping your child adjust emotionally

Even when an orthotic is properly fitted, in a fun design — your child may still experience frustration in wearing one. Most treatment plans require the orthotic to be worn continually, day and/or night. Be understanding that they may be somewhat apprehensive. Children don't want to stand out from their peers, so it can be difficult to wear an orthotic because it is noticeable to others.

To help a child adjust:

- Be positive and explain how much the orthotic helps. Encourage your child to think of it as a something that makes them *stronger, faster, and safer*.
- Talk with and prepare your child with answers for when others may ask about their orthotic.
- Share pictures and stories of other children or adults that also wear orthotics.





CREATING A CARE NOTEBOOK

Creating a care notebook is one tool that can help you organize important information about your child. Even with the electronic medical records that are utilized among hospitals, parents and caregivers still receive countless printouts and paperwork at each appointment. Having a portable medical summary for your child to take to appointments and keep all documents in one place will serve a vital purpose in the ongoing advocacy for your child's overall care. It will also prove helpful while working with your insurance provider and ensuring the coverage to expect with the different therapies and services being provided.

Creating a care notebook can help you:

- Keep track of medications, therapy, treatment plans, tests, and evaluation results.
- Organize contact information for health providers, social workers, therapists, and organizations.
- Keep track of communication from meeting sessions about your child (IFSP and IEP records).
- Help you to prepare for appointments and address questions and concerns.
- Keep track of all statements and communications between your insurance company.

How to get started:

- Build a notebook using a 3-ring binder, expandable folder or box and add dividers that are important to you. Examples can include: Portable Medical Summary, Quick Contact, Discharge Reports, Records, Logs, Therapy Calendar.
- Gather all existing information such as discharge reports, clinic visit summaries, immunization records, school plan, test results, and scheduled care plans.
- Clear page protectors make it easy to remove and update pages as needed. Some families have found it works best to have different notebooks for school and health records — find what works best for your family.



ORGANIZATIONS & FAMILY SUPPORT RESOURCES

PEDIATRIC STROKE SUPPORT GROUPS

IAPS SUPPORT NETWORK

The International Alliance for Pediatric Stroke (**IAPS**) **Support Network**, is an opportunity to connect with others one-on-one who have experience navigating the journey after pediatric stroke. The Support Specialists include parents of children of all ages, and young adults who experienced a stroke as a baby or child. To connect go to the IAPS Support Network page at iapediatricstroke.org/iaps-support-network/

AVM ALLIANCE SUPPORT NETWORK

AVM Alliance has created a Support Network of volunteer specialists who have firsthand experience in dealing with AVM-related issues. The Support Intake form is designed to be a user-friendly online tool that empowers parents to request personalized support tailored to their child's specific needs after an AVM diagnosis. For more information and to submit a request, go to the AVM Alliance Support Network page at avmalliance.org/avm-alliance-support-network

HOSPITALS

Hospital-based Pediatric Stroke Support groups are an area of need that are growing. Pediatric stroke support groups provide a reoccurring meeting place for parents to discuss topics, share stories, and help ease the isolation that is common after a child's stroke. Check with your child's medical team and ask if the hospital has this type of program for your family to join.

ONLINE

Virtual family-to-family support groups allow you to connect and ask questions on your schedule — without leaving the comfort of home. Having those connections with other families who have “been there” is a proven source of ongoing support that we encourage you to consider joining. We have included a number of these virtual support groups in this tool kit and on our website. You can find one that works best for you.

PEDIATRIC STROKE SUPPORT GROUPS ON FACEBOOK (META)

AVM Alliance

facebook.com/groups/325321586185434

Colorado Pediatric Stroke Group (Rocky Mountain Region)

facebook.com/Colopedsstroke

Famiglie #fightthestroke (Italy)

facebook.com/groups/fightthestrokeFTS

KISS Pediatric Stroke Support Group

facebook.com/groups/KISSPediatricStrokeSupport

Little Stroke Warriors Support Group (Australia and New Zealand)

facebook.com/groups/1214183908703615/

(MISS) Moms of Infant Stroke Survivors

facebook.com/groups/122984791109944

My Child had a Stroke

facebook.com/groups/119066951483785

Pediatric Stroke and Brain Injury Education

facebook.com/pedistroke

PEDIATRIC STROKE RELATED ORGANIZATIONS

International Alliance for Pediatric Stroke believes in the importance of being inclusive and sharing with families all of the organizations, programs and/or resources that currently exist to make a difference in supporting children and their families impacted by pediatric stroke. Please see our [Organizations](#) page on our website for a complete list.

American Stroke Association: stroke.org/en/about-stroke/stroke-in-children

AVM Alliance: avmalliance.org

Fight The Stroke (based in Italy): fightthestroke.org

HemiHelp (based in UK): contact.org.uk/hemihelp

International Pediatric Stroke Organization: internationalpediatricstroke.org

Pediatric Epilepsy Surgery Alliance: epilepsysurgeryalliance.org

Pediatric Stroke and Brain Injury Education: ygsa.org/pedistroke

The Stroke Association (based in UK): stroke.org.uk/childhood-stroke

The Stroke Foundation/Childhood Stroke (based in Australia): strokefoundation.org.au/about-stroke/learn/childhood-stroke



GENERALIZED SPECIAL NEEDS RESOURCES

Center for Parents Information & Resources (CPIR) serves as a central resource of information for families (parentcenterhub.org).

Child Neurology Foundation provides information, tools and resources, education, one-on-one support, and disorder directory for neurological conditions (childneurologyfoundation.org).

Family Voices is a national nonprofit, promoting quality health care for all children and youth, particularly those with special health care needs (familyvoices.org).

Parent to Parent USA provides emotional and informational support for families of children who have special needs (p2pusa.org).

Sibling Support Project is a national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with medical needs. Find a local SibShop program within your community (siblingsupport.org).

The Arc provides assistance to individuals with disabilities and their families in locating resources and community services (thearc.org).

The Brain Recovery Project provides research-based, reliable information to help parents and caregivers understand when a child's seizures are drug resistant. (brainrecoveryproject.org)

BOOKS & PUBLICATIONS

Healing the Broken Brain by Dr. Mike Dow

The Boy Who Could Run But Not Walk by Karen Pape, MD

Raising A Sensory Smart Child by Lindsey Biel

The Cerebral Palsy Tool Kit: From Diagnosis to Understanding by CPNOW

The Little Dark Spot: How I Came to Terms with My Baby's Stroke by Helene Louise

Mimi Learns to Walk by Helene Louise

I See You Little Naomi by Stefanie Boggs -Johnson

Daniel's New Friend adapted by Becky Friedman

The Luckiest Girl in the World: My Story of Struggle & Hope in Overcoming Pediatric Stroke by Jamie Lee Coyle

SPECIAL NOTE

For the purpose of this guide, we have included frequently used resources specific to Pediatric Stroke.

Our comprehensive website has more in-depth information on all of the topics covered in this Pediatric Stroke Family Tool Kit.

We recommend looking specifically under our **EDUCATION CENTER**, **IAPS SUPPORT NETWORK**, and **SUPPORT** sections. iapediaticstroke.org

RESOURCES SUPPORTING MEDICAL FINANCIAL ASSISTANCE

Alyssa V. Phillips Foundation, assists children with cerebral palsy to help with therapies or other medical treatments that insurance doesn't cover. The Foundation may provide financial support to those impacted by CP so that they can receive ongoing and necessary therapy treatments or medical equipment to increase independence where such benefits are not covered by medical insurance. (alyssavphillipsfoundation.com)

Cerner Charitable Foundation, is a public charity that provides funding for individual children with health needs when insurance and other financial resources have been exhausted. (cernercharitablefoundation.org)

CHASA (Children's Hemiplegia and Stroke Association), exists to improve the quality of life for children and their families affected by hemiparesis or hemiplegic cerebral palsy due to pediatric stroke or a variety of other conditions. CHASA helps with financial needs through their orthotic grant program, educational, retreat, and athletic scholarships. (chasa.org)

Laney Jaymes Foundation for Pediatric Stroke, is a 501(c)3 non-profit providing financial assistance in securing medical equipment and other adaptive products for children who have experienced stroke. Applications can be found at (laneyjaymes.org/who-we-support/)

Medicaid, is a federal government managed program by the Centers for Medicare & Medicaid Services. Learn more at (medicaid.gov)

My Gym Foundation, accepts applications for children with physical, cognitive, and/or developmental disabilities and those coping with chronic illness. Requests may include but are not limited to: rehabilitative therapy, assistive devices, medical equipment, and sensory items. (mygymfoundation.org)

Ronald McDonald House, a network of Chapters making children happier and healthier by keeping families close — giving them a place to rest and refresh. These programs, tailored to meet the urgent needs of each community, can be found in more than 64 countries and regions across the globe. Find your local RMHC: (rmhc.org/about-us)

The LENN Foundation, a 501(c)(3) charity that provides grant opportunities for children with cerebral palsy to receive pediatric intensive therapies to thrive in their everyday life. (thelennfoundation.org)

United Healthcare Children's Foundation, provides financial help/assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan. They aim to fill the gap between what medical services/items a child needs and what their commercial health benefit plan will pay for. (uhccf.org)

Wheel to Walk Foundation, is a non-profit organization that helps children with disabilities, 20 years of age and younger, obtain medical equipment or services that are not provided by insurance. This organization strongly believes that no child or young adult with special needs should go without items that could improve the quality of his or her daily life. (wheeltowalk.com)

These organizations, resources, and programs can change in what is available to support the medical financial assistance to families. It is important to refer to each organizations' individual website for all details and guidelines.



WORDS FROM THE HEART

“THE MOMENT WE FOUND HOPE AGAIN AFTER MY CHILD’S STROKE.” - FEATURED ON THE MIGHTY BLOG

There is no memory as vivid to any parent as the day they meet their child for the first time. It’s the day the anticipation comes full circle and they hear their child’s first cry into the world pierce the silence. The complications towards the end of my pregnancy made her cry even more monumental for me and even more reassuring that our beautiful girl was here. I finally got to hold her, see those beautiful red curls and soak in those 10 tiny toes and fingers — my little sunshine mixed with a hurricane was here.

Those first weeks home were as beautiful as they were difficult. While most newborns sleep, our daughter had difficulty, sleeping no more than a two-hour stretch at a time. While most newborns build an appetite and yearn to eat, our infant would eat for minutes at a time and then cry with frustration and discomfort. We were at a loss and had many questions, but we were assured at each of her appointments that she was healthy and this phase was all a part of being an infant.

As weeks turned into months and sleep and eating continued to prove difficult for her, we had many appointments. There were many discussions on colic, acid reflux and allergies. We sought support from lactation specialists, therapists trained in reflux and made countless morning calls to her pediatrician to be seen that day after a horribly hard night. All attempts proved futile with the constant reassurance that she was healthy.

As my daughter began taking notice of toys and figuring out her world, I started to notice that she never unclenched her left fist. I had to try with all my might to get her little thumb out of her fist to introduce toys to her left hand or to clip her tiny nails. It was strange to me, but I didn’t have any knowledge to be overly concerned. At first, we believed she was born to be a righty. When she continued to disregard her left hand in play, I became scared that her arm or a nerve may have gotten hurt during my delivery.

It was at her six-month checkup that her pediatrician took notice with my concern. But, he added to my concern by sharing the possibility of a stroke — words that, no matter how hard anyone tried to explain away the rarity of it, I couldn’t get out of my mind. A child having a stroke — *how is that even possible?*



TRAPPER – FATHER TO ADDISON,
PERINATAL STROKE WARRIOR

"Regardless of what the MRI entailed or that stroke diagnosis, they are words and they are pictures. It all serves an undeniable purpose, but it has been my own daughter, and it will be your own child, that will define themselves."

We had a month of waiting to be seen by a specialist who performed a sedated MRI. In that time I had poured over Google to scour for every possibility and every relatable story. I was filled with anxiety, questioning myself, my pregnancy and any new behavior my daughter showed. I was lost, overwhelmed and scared. Friends and family tried to reassure me, to help calm my feelings by saying everything would be all right and that there must be an easy explanation.

When the call finally came and the doctor shared the results from the MRI, there was nothing easy about the explanation. Her words came across in slow motion, indicating the results reflected a stroke. The relief I had hoped to feel, that I had longed for after months of knowing there was something wrong, wasn't there — only new questions and emotions to struggle through.

That following week, we sat together huddled over a computer screen with the neurologist, scared and unsure of what all this meant for our little girl's future. Would she ever walk? Would she ever talk? Would she have another stroke? The doctor began to show each scan from her MRI, different angles and "slices" of images taken of my daughter's brain. The room filled with medical terms and more uncertainty until she paused on one image — an image from my daughter's chin up to the top of her head. It wasn't the dark void in the image on my daughter's right side of her brain that I focused on anymore. Now I could see the outline of her little face, the way her chubby cheeks left an outline even in an X-ray, and there she was. In that moment among the fear and uncertainty, I sat grounded, brought back to my senses that no matter what we could come to learn about this diagnosis, it did not define my daughter. She was still right there. My little sunshine mixed with a hurricane.

It's been nearly five years, and not only have we learned so much about stroke, but we also learned that we truly have to take it one day at a time. To say that it has always been easy, would be a lie. There have still been moments of feeling lost in emotion and worry. It's human and it's part of being a parent.

Families often want to know if this ever gets any easier. That answer is yes, but the timing is different for all of us. Hold fast that no matter the diagnosis, an image from a MRI — it is all a tiny part of the picture. Your child will make their way in overcoming and becoming so much more than you could ever imagine. Take Heart.

Kaysee Hyatt - Mother to Addison, Perinatal Stroke Warrior



WORDS FROM THE HEART

“WHEN I WAS TOLD I MAY NEVER DANCE AGAIN AFTER A STROKE AT AGE 10.” - FEATURED ON THE MIGHTY BLOG

When I was 6 years old, I was diagnosed with cavernous hemangiomas, a hereditary disease that causes weak veins in the brain. The veins can leak and cause a seizure or stroke. My doctors advised my parents that it was dangerous for me to play contact sports, so I took dance classes. I became a competitive dancer and trained 10 hours a week in dance and tumbling. I went along with my life not worrying about the time bomb in my head.

When I was 10, I was at the beach surfing when I had a hemorrhage in my brain stem, which caused a severe stroke. The bleed in my brain stem did not stop, and I had to have emergency brain surgery to save my life. Later, I found out the doctors did not know if I would survive, and asked my parents if they would sign papers to donate my organs. When I woke up, I was completely paralyzed. I could not eat, speak, or walk. I felt like I was trapped inside myself. I saw the worry on everyone's faces and wanted to scream, “I'm here!”

I was transferred to a rehab hospital and received intense therapy. When I was told I may never dance again, I used my training as a dancer to help me focus, even when I was so tired I could barely hang on. It took two months of hard work and determination, but I was able to walk out of the hospital.

I used dance and music as a large part of my recovery. I could do things to music that I couldn't do at the therapy center. I was fortunate enough to have a very supportive dance studio, teachers, and peers who understood how important dancing was to me. When I could not stand, my dance teachers would hold me up. I was back on a competition team a few months after I got out of the hospital. I continue to compete to this day, and have received many awards and honors for my unique style of dance and the way I share my story through dance. I am still partially paralyzed, and have not let that stop me.

Three years ago, I co-founded a class called the “Rising Stars” at my dance studio. This class is a chance for kids with physical and cognitive challenges to experience the same healing and joy that dance has given me.



GRACIE DORAN – PEDIATRIC STROKE WARRIOR

“It is a miracle that I lived through everything, and I believe I’m alive for a reason. I’m here to show the world that you can’t control what happens to you, but that you can control what you do because of what happened.

Your disability, no matter what it is, does not have to define you.”

GET CONNECTED

WEB: graciedoran.com

TWITTER : @daysofgrace99

EMAIL: daysofgrace99@gmail.com

Dance helped me recover and find my purpose after I got sick, and there is nothing that makes me happier than to see the kids smiling when they start to dance.

It is a miracle that I lived through everything, and I believe I’m alive for a reason. I’m here to show the world that you can’t control what happens to you, but you can control what you do because of what happened. You control your future, so when someone tells you that you can’t do something, show them you can. Your disability, no matter what it is, does not have to define you.

I have been fortunate to share my story at schools and to community members. I speak about resilience and showing people that you can do anything you can set your mind to. I have a favorite quote from Audrey Hepburn, “Nothing is impossible — the word itself says I’m possible.” I share the message that our differences don’t define us as people. What is “normal,” and who wants to be normal anyway? Our differences make us unique as individuals and beautiful in our own way. We may be very different on the outside, but we all share hopes and dreams. We all want to grow up and be successful and have a fulfilling life of our own.

My hope is to continue to be an advocate for people like me who may not have a voice. I want to continue to make an impact and be proud of what I’ve done. Someday, I want to be able to share the stories of my life with my children and grandchildren, and make them proud.

This is my disABled life.

Gracie Doran - Warrior



IMPORTANT NOTES

GLOSSARY OF MEDICAL TERMS

COMMON MEDICAL PROFESSIONALS

Cardiologists study the heart and its functions.

Developmental Pediatricians are specially trained pediatricians who are primarily concerned with the evaluation of a child's development.

Developmental Psychologists study the physiological, cognitive, and social development that takes place throughout life. Some specialize in behavior during infancy, childhood, and adolescence.

Epileptologists specialize in the treatment of epilepsy.

Genetic Counselors are specialists who assess whether the stroke may be due to an inheritable condition.

Hematologists diagnose and treat diseases of the blood. A child who has had a stroke may see a hematologist for blood tests to determine if there is a clotting disorder.

Neonatologists are specially trained pediatricians who study the development and disorders of sick newborn children.

Occupational Therapists (OT) help children improve their ability to perform tasks in their daily living. They help children succeed in their "occupation" of learning, playing, and growing. They may help children with tasks such as improving hand function, strengthening hand, shoulder, and torso, and eating skills.

Orthotists are responsible for the provision of orthoses (supportive devices such as braces) to children with muscular and skeletal disabilities.

Neuro-Ophthalmologists are medical doctors with advanced education and experience in evaluating and treating disorders of the eye and brain. They understand how complex nervous system conditions can contribute to vision problems.

Pediatric Neurologists diagnose and treat diseases that involve the nervous system in children. Children may see a neurologist to discover the cause of their condition, recommendations for treatment, diagnosis and treatment of a stroke, seizure disorder (epilepsy), and for other information concerning their condition.

Pediatric Neuropsychologists focus on how learning and behavior are related to brain development. This is a good resource for early school age children.

Pediatric Ophthalmologists can evaluate how well the eyes work together, examine vision and health of eyes, prescribe glasses, diagnose eye disease, and perform corrective eye surgery.

Pediatric Orthopedic Surgeons are concerned with deformities, injuries, and diseases of the bones, joints, ligaments, tendons, and muscles. Treatment provided by an orthopedist may include manipulation, the fitting of braces or other appliances, exercising, and surgery.

Physiatrists (also called Physical Medicine and Rehabilitation Specialists) are familiar with rehabilitation from injuries including stroke.

Physical Therapist (PT) provide services that help restore function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities of patients suffering from injuries or disease.

Speech-Language Pathologist (SLP) assess, diagnose, and treat speech, language, cognitive, communication, voice, swallowing, fluency, and other related disorders; **Audiologists** identify, assess, and manage auditory, balance, and all other neural systems.

GLOSSARY OF MEDICAL TERMS

Ankle Foot Orthotic (AFO): A brace that is worn on the lower leg and foot to support the ankle and hold the foot in the correct position. It also helps with stability.¹³

Apnea: An unexplained episode of cessation of breathing for 20 seconds or longer. Apnea is more common in preterm infants.¹²

Aquatic Therapy: Therapy provided from a licensed therapist in a warm pool to promote a reduction in muscle tone, improve flexibility, and provide global relaxation. Uniform support and fluid resistance of the water provides stability to the patient. Near zero gravity and buoyancy effectively reduce the patient's body weight, making it easier to move.

Arterial Ischemic Stroke (AIS): Brain injury caused by blockage of blood flow in an artery caused by a blood clot and/or narrowing of the artery.¹⁴

Arteriovenous Malformation (AVM): AVMs are abnormal tangles of arteries and veins. These abnormalities are typically congenital and are present at birth. They usually are not detected unless they cause seizures, weakness, or have ruptured and bled in the brain. AVMs most often occur in the spinal cord and in the brain but can develop elsewhere in the body.^{33, 54}

Botulinum Toxin type A: Most commonly called Botox. Botox is a therapeutic muscle-relaxing medicine. It is often used to reduce stiffness of muscles and to help with muscle spasms.¹³

Cerebral Angiogram: A procedure that uses a special dye (contrast material) and x-rays to see how blood flows through the brain.¹⁵

Cerebral Palsy (CP): Difficulty with physical movements that result from an abnormality or injury to the brain at birth. Medical professionals may describe a perinatal stroke survivor using the term 'Cerebral Palsy'. Stroke can be a cause of CP.¹³

Cerebral Sinovenous Thrombosis (CSVT): A clot in a vein blocks drainage of blood from the brain. This can cause a stroke.²⁶

Childhood Apraxia of Speech (CAS): A speech disorder in which a child's brain has difficulty coordinating the complex oral movements needed to create sounds into syllables, syllables into words, and words into phrases. Typically, muscle weakness is not to blame for this speech disorder.¹⁶

Childhood Stroke: A category of stroke that includes ages 28 days old to 18 years old.³

Computed Tomography Scan (CT scan): This is a specialized procedure that takes multiple x-rays at various angles and then integrates all of them into pictures of high resolution.²⁰

Congenital Heart Defect (CHD): CHDs are present at birth and can affect the structure of a baby's heart and the way it works. They can affect how blood flows through the heart and out to the rest of the body. CHDs can vary from mild (such as a small hole in the heart) to severe (such as missing or poorly formed parts of the heart).¹⁸

GLOSSARY OF MEDICAL TERMS

Constraint-Induced Movement Therapy (CIMT): This therapy is an innovative, scientifically supported method of upper extremity rehabilitation for children with neuromotor impairments. CIMT involves constraint of the non-affected upper extremity in combination with intensive therapy.¹⁷

Craniectomy: A surgery done to remove a part of the skull in order to relieve pressure in that area when there is swelling in the brain.¹⁹

Durable Medical Equipment (DME): Any equipment that provides therapeutic benefits to a patient in need because of certain medical conditions and/or illness. Examples include: leg/foot braces, wheelchair, walker.²¹

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.²²

Dysarthria: A motor speech disorder in which the muscles that are used to produce speech are damaged, paralyzed, or weakened.⁵¹

Dyspraxia: Difficulty in planning and carrying out skilled non-habitual motor acts in the correct sequence. Thought to be due to difficulty in formulating the plan of action.⁴⁸

Electrical Stimulation (E-Stim): Electrical stimulation or neuromuscular electrical stimulation (NMES) is a technique used to elicit a muscle contraction using electrical impulses. Electrical current is then sent from the unit to the electrodes and delivered into the muscle causing a contraction.²⁴

Electrocardiogram (ECG/EKG): Non-invasive test that records the electrical activity of the heart and can show if there is a heart condition present.²³

Electroencephalogram (EEG): A study used to measure the electrical activity of the brain. It can assist in diagnosing seizures.²³

Epilepsy: Sometimes called a seizure disorder, is a chronic medical condition produced by the temporary changes in the electrical function of the brain, causing seizures. Stroke may be one cause of epilepsy.²⁵

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”.²⁷

Hemiparesis: A slight weakness — such as mild loss of strength — in a leg, arm, or face.²⁹

Hemiplegia: A severe or complete loss of strength or paralysis on one side of the body.²⁹

Hemispherectomy: A surgical procedure which involves total, or partial removal of an affected cerebral hemisphere or disconnecting the affected cerebral hemisphere from the unaffected side in the brain. This procedure may be used for patients with medically intractable epilepsy.²⁸

GLOSSARY OF MEDICAL TERMS

Hemorrhagic Stroke: Caused by a weakened vessel that ruptures and bleeds into the surrounding brain. The blood accumulates and compresses the surrounding brain tissue.³⁰

Hydrocephalus: An abnormal buildup of fluid in the ventricles (cavities) deep within the brain. This excess fluid causes the ventricles to widen, putting pressure on the brain's tissues.³²

Hypertonia: A condition in which there is too much muscle tone so that arms or legs, for example, are stiff and difficult to move.³¹

Hypotonia: A medical term used to describe decreased muscle tone. Infants with hypotonia have a floppy quality or “rag doll” appearance.³¹

Intracranial Hemorrhage: Sometimes called “brain bleed”— bleeding between the brain tissue and skull or within the brain tissue itself. It can cause brain damage and be life-threatening.³⁴

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.¹³

Magnetic Resonance Arteriography (MRA): A non-invasive test that is used to visualize arteries and their blood flow.¹³

Magnetic Resonance Imaging (MRI): A process that creates high-quality pictures of the inside of the body. An MRI uses a large magnet to create these pictures.¹³

Magnetic Resonance Venography: Non-invasive test that is used to visualize veins and their blood flow.¹³

Mirror Therapy: The principle of mirror therapy (MT) is the use of a mirror to create a reflective illusion of an affected limb in order to trick the brain into thinking movement has occurred without pain, or to create positive visual feedback of a limb movement. It involves placing the affected limb behind a mirror, which is sited so the reflection of the opposing limb appears in place of the hidden limb.³⁵

Moyamoya Disease (pronounced MOY-a-MOY-a): A rare neurological disorder involving the progressive narrowing of two of the major arteries (internal carotid arteries) supplying blood to the brain. The cause of Moyamoya disease is unknown, although rare familial cases have suggested a genetic influence.³⁶

Occupational Therapy (OT): Occupation refers to all of the “jobs” that make up our daily life, whether you are child or a young adult. An Occupational Therapist will evaluate your child’s ability to perform self-care, play, and school skills at an age-appropriate level. The goal of OT is for the child to participate as actively and fully as possible in all areas — self-care, play, and school skills.

Physical Therapy (PT): Also known as Physiotherapy. A type of treatment that promotes independence, increases participation, facilitates motor function and development, improves strength and endurance, enhances learning opportunities, and eases challenges with daily caregiving.

GLOSSARY OF MEDICAL TERMS

Plasticity: Also known as neuroplasticity, refers to the brain's ability to reorganize connections and pathways.³⁷

Praxis: The ability to interact successfully with the physical environment, to plan, organize, and carry out a sequence of unfamiliar actions and to do what one needs and wants to do.⁴⁸

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".³⁸

Seizures: Changes in the brain's electrical activity. These changes can cause dramatic, noticeable symptoms, or in other cases no symptoms at all. Because some seizures can lead to injury or be a sign of an underlying medical condition, it's important to seek treatment if you experience them.³⁹

Spasticity: A condition in which muscles stiffen or tighten, preventing normal fluid movement. The muscles remain contracted and resist being stretched, thus affecting movement, speech, and gait.⁴⁰

Speech-Language Pathologist (SLP): A professional who evaluates communication skills and treats speech and language disorders. This can include both receptive and expressive language, auditory processing, memory, articulation, fluency, oral-motor development, and feeding skills. The speech pathologist may also screen a child's hearing and make a referral for further evaluation if needed.

Supra Malleolar Orthosis (SMO): A brace that supports the leg just above the ankle. It is the shortest of braces and helps to keep the heel in the correct position.⁴¹

Transcranial Magnetic Stimulation (TMS): TMS technology is a non-invasive method used to study the electrical properties of the brain. The focused magnetic field created enters a small area of the brain and activates the cells (neurons) in that area. When applied over the movement (motor) parts of the brain, this can create a "twitch" in a muscle which is measured with some stickers placed over that muscle, usually in the hand. Early evidence suggests that repeated applications of TMS with a special machine (called repetitive or "rTMS") may have some lasting effects on brain function.⁴⁶

Transient Ischemic Attack (TIA): A temporary period of symptoms similar to those of a stroke. A TIA usually lasts only a few minutes and doesn't cause permanent damage. It can serve as both a warning of a future stroke and an opportunity to prevent it.⁴²

UCBL: Also known as UCB, a shoe insert that was named after the laboratory where it was researched and developed (University of California Berkley Laboratories). It is used to stabilize a flexible foot deformity.⁴³

Ultrasound: An imaging method that uses high-frequency sound waves to produce images of structures within your body.⁴⁴

Vasculitis: Swelling of blood vessels in the body. This condition can happen when the immune system attacks the blood vessels.⁴⁵

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International Alliance
for Pediatric Stroke
iapediatricstroke.org

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