

TEAM LUK3
HOPE FOR MINDS

Brain Injury and Your Child

A resource guide for parents
and caregivers of children
with brain injuries

Updated June 2024



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	<p>Mathew Cesari</p>	

Introduction



Message of Hope

OUR MISSION IS TO ENRICH THE LIVES OF CHILDREN WITH A BRAIN INJURY AND GIVE HOPE TO THEIR FAMILIES THROUGH SUPPORT AND EDUCATION.

Since the beginning, Team Luke Hope for Minds' main focus and mission has been to serve families who are caring for a child with a brain injury through emotional support, financial assistance, educational resources, advocacy services and more. We feel we have the unique ability to provide help and hope while enriching the lives of children impacted by a brain injury.

According to the Texas Brain Injury Alliance, an infant, child, teenager, or adult in the U.S. sustains a traumatic brain injury every 21 seconds. There is a void, however, in access to services for children who have brain injuries. That is where Team Luke Hope for Minds steps in. We want to be a source of hope and guidance.

At the heart of our services is the conviction that the health and well-being of these children can improve over time if families have access to educational materials, resources, therapeutic services and adaptive equipment for their children. The emotional, physical and financial strain of caring for your child is undoubtedly taxing on you and your family.

The pain and frustration of your child's injury may seem overwhelming. Words can only begin to describe the hurt you and your family are experiencing.

When it feels like the world is telling you to give up, remember that there is always hope.

ANNUAL MAKING CONNECTIONS PEDIATRIC BRAIN INJURY CONFERENCE AND RESOURCE FAIR

Every fall, Team Luke Hope For Minds hosts a two-day long conference that connects families and provide resources and education for caregivers. Attendees explore services and products, as well as listen to presentations on a variety of relevant topics.

OUR STORY

JD

In 2008, an 11-year-old boy named JD suffered an anoxic brain injury from a non-fatal drowning incident in a hot tub. The family saw "life as normal" change that Saturday afternoon as they and their four children faced the uncertainty of life ahead. As JD underwent extensive treatment for his injuries over a 6-month hospital stay, the community stepped up and supported the family both financially and emotionally through financial support and prayer. "Pray, Pray, Pray for JD" and "Hope4JD" became the slogans of these support efforts.

As JD began treatment, his family struggled with the lack of information and guidance, as well as the mounting expenses for items such as house renovations, transportation, medical equipment for their home, and recovery-based therapies not covered by insurance. They received significant financial support from their community and a decision was made to form Hope4JD (later to become Hope4Minds) to help families experiencing the same struggles. Approved in December 2011, HOPE4JD (dba HOPE4MINDS(2015), later to become Team Luke Hope For Minds(2018), is a 501(c)(3) nonprofit organization (Tax ID #32-0351208) that supports families with children who have suffered an acquired brain injury.

Luke

In 2015, a 9-year-old boy named Luke and a friend were left unsupervised in a golf cart while playing at a friend's house when they had an accident. When his dad arrived at the hospital he was told, "Luke has been in cardiac arrest for 7 minutes. He has suffered head and chest trauma." Life changed that afternoon

in July for the Siegel family. Just twenty days before the accident Tim Siegel, Luke's dad, resigned as the tennis coach at Texas Tech (where he had been the past 23 years) to spend more time with his wife Jenny and their four beautiful children. Luke spent the next six months in extensive treatment, brain surgeries, and therapy. Luke's MRI was so bad the neurologist told the Siegel family that Luke would never use his voice or his limbs. "My little Luke was the greatest fighter I've ever seen," says Tim Siegel. The Lubbock community stepped up and supported the Siegel family after the accident. "Fight Like Luke" and "Pray for Luke" became regular phrases in the town's vocabulary.

The Merge

In 2017, Tim Siegel met with Ronda Johnson in Austin to learn more about Hope4Minds. Immediately after that meeting, Tim knew the impact they could make together to support other children like Luke and JD. In 2018, the two organizations merged to create Team Luke Hope For Minds.

In August 2021, our beloved friend and hero, Luke Siegel, gained his wings after complications related to COVID-19. The outpouring of love, prayer, and support across the nation has been overwhelming and a testament to the incredible impact Luke made on the world. Luke was able to inspire thousands without ever saying a word. His legacy lives on each and every day as Team Luke Hope For Minds continues to enrich the lives of children with brain injuries by giving hope to their families through support and education.

"JD is doing really good," said John Hartman, JD's father. "He has recently started putting words in context when a person can't understand him. It is amazing that he is still making progress in his recovery after 14 years," said John.

REASONS TO HOPE

Long-term studies on the recovery of severely brain injured patients have produced data that is more

encouraging than what your child's physician might provide. Medical researchers are constantly evaluating new drugs and therapies to improve the recovery of brain injured children. It is possible that technological and medical advances in the future will one day improve the quality of life of brain injured children.

YOUR MINDSET

Being the primary caregiver for your child means that you play one of the biggest roles in their recovery. Thus, having the right mindset is vital to their rehabilitation. Remember, your child's injury and recovery is going to be a process, long and hard, but not impossible. You do not have to bear this burden alone. Be willing and open to accept support from others. People want to help you, so let them! *It's in God's Hands* is Executive Director of Team Luke Hope For Minds, Tim Siegel's, honest and moving account of the grief he has experienced since the day of Luke's accident and how his relationship with his son has changed and grown. Siegel's second book, *Fight Like Luke: Transforming Grief into Love, Strength, and Faith* was released early 2023. Both books are available on Amazon.

DISCLAIMER

With a servant's heart, we lovingly share the following information. It is our great hope this Resource Guide provides you enlightenment and comfort in the challenging journey ahead, and is provided for informational purposes only.

Referenced material was gathered from multiple sources out of the vast wealth of information available to families and the public at large. By inclusion or reference in this Guide, we take no position nor embrace or advocate any particular medical view or opinion expressed. Through sharing information about head injury and brain damage, it is not the intent, purpose nor goal of Team Luke Hope for Minds, its representatives and affiliates, to offer any medical opinion, assessment or advice whatsoever.

Symptoms and complications of brain damage can vary greatly from child to child, and fluctuate over time. Note that merely because a symptom,

complication or condition is identified in our Guide does not mean it will manifest in your child.

Accordingly, our Resource Guide should not be relied upon in any way as a diagnostic aid to your child's condition nor utilized in making decisions about your child's health, condition or ongoing treatment. You should consult a qualified physician or other trained healthcare professional on all such issues and with any questions you may have.

About Brain Injury



About Brain Injury

ACQUIRED BRAIN INJURY (ABI)

According to the World Health Organization, an acquired brain injury is any “Damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. These impairments may be temporary or permanent and cause partial or functional disability or psychosocial maladjustment.”⁹

There are two types of acquired brain injuries. Physical damage caused by a forceful impact to the head, such as from an auto accident or a fall, is called a traumatic brain injury (TBI). When the brain is damaged from a lack of oxygen, such as from a nonfatal drowning or choking accident, an anoxic brain injury occurs. Congenital or progressive conditions like Parkinson’s Disease and Alzheimer’s are not considered acquired brain injuries.

TRAUMATIC BRAIN INJURY (TBI)

Traumatic Brain Injury affects almost 2.5 million people every year, and encompasses injuries that are obtained from an external force.¹ Traumatic brain injuries are considered a type of acquired brain injury and refer to any injuries that have come from an external force or impact. Severe TBI produces significant brain swelling which can reduce oxygen flow and subsequently produce anoxic injuries after the initial impact.

SECONDARY BRAIN INJURY

A Secondary Brain Injury is an injury that is indirect of the initial injury and may take days or weeks before presenting. Following a traumatic injury to the head, there are often unexpected risks posed to the brain due to the physical injuries. Secondary injuries may result from increased pressure inside the skull from swelling that will naturally occur from head trauma.²

Subsequent changes in oxygen and blood flow in the brain may pose dangers to functionality and increase the risk of infection. When traumatic injuries to the

head occur, it is important to understand the risks involved and to be prepared for treatments that can prevent long-term damage.

BRAIN ELASTICITY

There is increasing evidence supporting the idea that children’s brains are extremely malleable, and exhibit plasticity!³ Your child’s brain is still growing and developing, and remember that despite the extent of your child’s injuries, their brain holds the potential to recover and grow. Understanding that the brain can experience a tremendous amount of growth repair at young ages stresses pursuing therapy and rehabilitation.

Extensive research has shown the brain cycles through several ‘critical periods’ of development which are concentrated during our early years, prior to adulthood.^{4,5}

Engaging in therapies and treatments as soon as possible and early on can pay great dividends in your child’s rehabilitation

Typical Diagnoses of TBI/ABI

Normally, healthcare professionals will diagnose brain injuries using a combination of patient records, imaging results from tests like CT scans or MRIs, and the discretion of the hospital team.

A traumatic or anoxic brain injury will often be diagnosed based on severity and may be classified as ‘moderate’ or ‘severe’ based on the information provided to your healthcare professional or the hospital team.

At the hospital, doctors may use ratings and scales to convey the severity of your child’s injury. These include but are not limited to the Glasgow Coma Scale, the Ranchos Los Amigos Scale, in addition to other severity level terms like the ‘Duration of loss of consciousness (LOC)’ and ‘Post-traumatic amnesia (PTA)’. These scales and levels of severity are detailed below. Understanding the information these scales convey will help you better communicate with your team of healthcare providers.

GLASGOW COMA SCALE

Glasgow Coma scale (GCS) is a common scoring system used to score the responsiveness (and likely level of brain damage) in patients. Patients receive points for their ability to respond with and control their eyes, verbal, and motor movements such as hands and legs. It is important to consider that locked-in patients are very conscious but would score very low on the GCS. In other words, an inability to respond does not necessarily indicate a lack of awareness or consciousness. The GCS is measured on a scale of 3-15, with 15 being normal and 3 as most severe.

RANCHOS LOS AMIGOS SCALE

Ranchos Los Amigos scale is an evaluation tool used by the rehabilitation team. The eight levels describe the pattern or stages of recovery typically seen after a brain injury, measuring levels of awareness, cognition, behavior, and interaction with the environment. This helps the team understand and focus on the person’s abilities and design an appropriate treatment program. Each person will progress at his or her own rate, depending on a variety of factors, including the severity of the

brain damage, the location of the injury in the brain, and length of time since the brain injury. Some individuals will pass through each of the eight levels, while others may progress only to a certain level.

DURATION OF LOSS OF CONSCIOUSNESS

Duration of loss of consciousness (LOC) is a common medical term used to describe a patient’s awareness and is classified in three ways. These classifications are based on length of unconsciousness, with mild being less than 30 minutes, moderate being 30 minutes to 6 hours, and severe being any period of unconsciousness greater than 6 hours.⁷

POST-TRAUMATIC AMNESIA

Post-traumatic amnesia (PTA) describes inability to demonstrate memory of their environment from the moment of injury until the patients can convey a continuous memory of their environment.^{7,8}

GROSS MOTOR FUNCTION CLASSIFICATION

The gross motor function of children and young people with cerebral palsy can be categorized into 5 different levels using a tool called the Gross Motor Function Classification System GMFCS looks at movements such as sitting, walking and use of mobility devices. It is helpful because it provides families and clinicians with: a clear description of a child’s current motor function, and an idea of what equipment or mobility aids a child may need in the future, e.g. crutches, walking frames or wheelchairs.

OTHER POSSIBLE TESTS YOUR CHILD MAY UNDERGO:

- Computerized Axial Tomography Scan (CT or CAT scan): A method which can be used to acquire detailed images of the brain
- Electroencephalogram (EEG): A measure which detects electrical activity in the brain
- Magnetic Resonance Imaging (MRI): A technique to acquire detailed images of brain

Lobes of the Brain

Below is some helpful basic knowledge about the different areas of the brain.

FRONTAL LOBE

Frontal Lobe is located the most anteriorly in the head.

The frontal lobe is heavily involved in our consciousness and how we respond to the world around us and our environment.² Functions include communication and language as well as motor skill coordination.

Potential problems include:

- Paralysis as a result of damage
- Impairment in cognitive abilities like focusing, behavior, memory loss and complex movements
- Difficulty with speaking (aphasia)

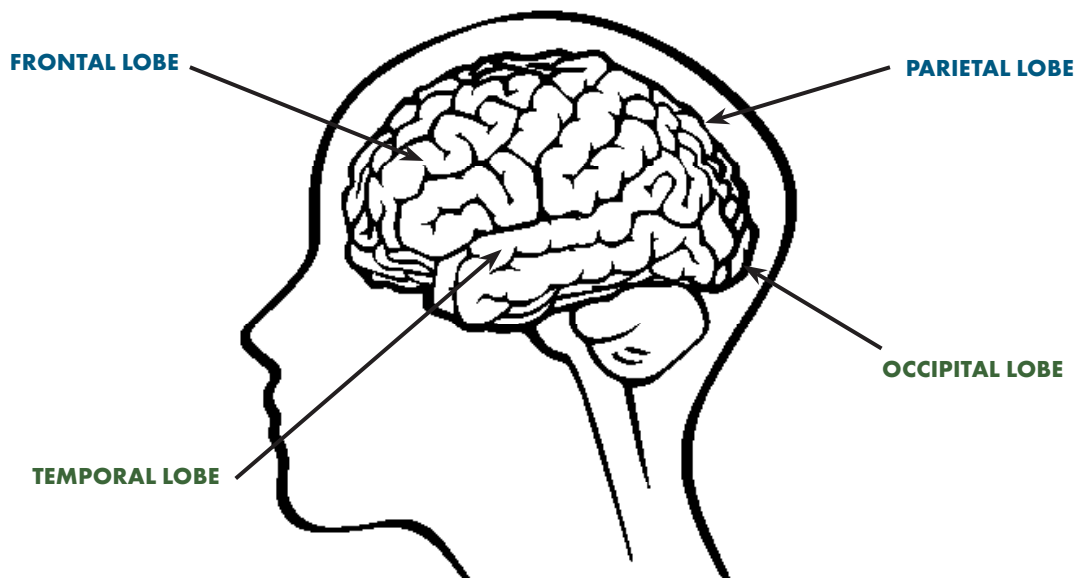
PARIETAL LOBE

Parietal Lobe is located near the top and back of the head.

The parietal lobe is involved with voluntary movements as well as focusing attention and the integration of our sensory system.²

Potential problems include:

- Difficulties with multitasking
- Trouble distinguishing right from left
- Impaired hand-eye coordination
- Inability to read or write well



TEMPORAL LOBE

Temporal Lobe is located above the ears at the sides of the head.

The temporal lobe is involved in hearing and memory.²

Potential problems include:

- Short-term memory impairment
- Disturbances to attention span and ability
- Changes to behavior
- Facial recognition deficiency

OCCIPITAL LOBE

Occipital Lobe is located most posteriorly, at the back of the head.

The occipital lobe is primarily involved with vision.

Potential problems include:

- Difficulty with vision
- Problems with distinguishing details in objects
- Reading and writing impairment

Common Brain Injury-Related Terms

Acute Care Short term medical treatment, typically occurring soon after injury.

Affect Behavior that is the observable representation of emotion.

Agnosia Failure to recognize familiar objects.

Agraphia Inability to express thoughts in writing.

Alexia Inability to read.

Anomia Inability to recall names of objects.

Anosmia Loss of sense of smell.

Anterograde Amnesia Inability to remember ongoing events.

Apathy Lack of interest, enthusiasm, or concern.

Aphasia (receptive) Loss of ability to understand language.

Aphasia (expressive) Loss of ability to formulate language.

Apraxia Inability to carry out purposeful movement.

Asterognosia Inability to recognize objects by touch.

Ataxia Difficulty with muscle coordination.

Atrophy Loss of brain tissue.

Bilateral Referring to both sides of the brain or body.

Brain Plasticity Referring to the ability for the brain to adapt and reorganize neural pathways following experiences and/or injury.

Brain Stem Area at the base of the brain responsible for controlling and regulating vital body functions.

Cerebral Spinal Fluid (CSF) A clear, colorless fluid that protects the brain and spinal cord.

Cognition Process of knowing or perceiving.

Computerized Axial Tomography Scan CT or CAT scan - A method which can be used to acquire detailed images of the brain.

Confabulation Verbalizations with no basis in reality.

Contra-coup Injury An injury resulting from the brain contacting the skull on the side opposite from where the original impact occurred.

Contusion Bruise of brain tissue.

Cortical Blindness Loss of vision due to visual cortex damage.

Critical Period Time when the brain may be particularly adaptable to new information.

Dysarthria Difficulty in speaking due to motor cortex or brain stem damage.

Dysmetria Inability to stop a movement at the desired point.

Dysphagia Difficulty in swallowing.

Echolalia Imitation of sounds or words without comprehension.

Edema Swelling of brain tissue.

Electroencephalogram (EEG) A measure which detects electrical activity in the brain.

Executive Functions A set of cognitive processes including attentional and inhibitory control, working memory, and cognitive flexibility.

Extremity Referring to the arms (upper extremities) or the legs (lower extremities).

Hemiplegia Paralysis of one body side.

Hemiparesis Weakness of one body side.

Hemorrhage Excessive loss of blood due to burst artery.

Infarction The obstruction of blood supply to the brain.

Intra-cranial pressure A measure of the pressure of brain tissue and CSF.

Ischemia Insufficient blood supply to the brain.

Lability Drastic changes in emotions without apparent reason.

Locked-in syndrome Neurological disorder characterized by complete paralysis of voluntary muscles, except for those controlling eye movement. Typically occurs as a result of damage to the brain stem.

Magnetic Resonance Imaging (MRI) A technique used to acquire detailed images of the brain

Motor Cortex Area of the brain where voluntary muscle movements originate.

Neuroinflammation Swelling of brain tissue.

Nystagmus Involuntary movement of the eyes.

Perception The ability to see, hear, or become aware of one's surroundings.

Perseveration Repeating a word or phrase insistently or redundantly.

Proprioception Sensory awareness of the position of body parts.

Retrograde Amnesia Inability to recall or remember events which happened prior to injury.

Secondary Brain Injury An injury that is indirect of the initial injury. These injuries may take days or months before presenting.

Sensory Cortex Area of the brain responsible for interpreting tactile sensory information.

Shunt Device used to divert excess fluid away from the brain.

Spasticity Characterized by an inability to control tight or stiff muscles.

Spontaneous Recovery The ability for the brain to recover certain lost functions in the absence of external therapies.

Verbal Apraxia The inability to translate conscious speech plans into motor plans.

Visual Field Defect Not seeing objects in specific visual field regions.

OTHER NOTABLE TERMS

Coma A state of altered consciousness in which a person cannot be fully awakened. They may fail to respond normally to painful stimuli, light, or sound; may lack a normal wake-sleep cycle; and usually does not initiate voluntary actions.

Unresponsive Wakefulness Syndrome (UWS) Awaken from coma (that is, open the eyes) but remain unresponsive (that is, only showing reflex movements without response to command).

Vegetative State (VS) The older term for Unresponsive Wakefulness Syndrome (UWS).

Minimally Conscious (MCS) A condition of severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated.

Locked-in Syndrome A neurological disorder characterized by complete paralysis of voluntary muscles in all parts of the body except for those that control eye movement.

Resources for Support



Non-Profit Resources

Team Luke Hope for Minds

Team Luke Hope for Minds enriches the lives of children with a brain injury and gives hope to families through support and education.

Ragan's Hope

Ragan's HOPE is committed to helping parents of children with serious ongoing medical conditions or injuries endure the initial impact and embrace the future in the name of Christ.

Critically Loved

Critically Loved seeks to positively impact the lives of families with chronically or critically ill children by assisting them in navigating hospital stays, bill payment, and schooling issues as well as providing educational, recreational and spiritual support to foster community.

Who Is Carter Foundation

The Who Is Carter Foundation changes the conversation around childhood brain injury - whether among physicians, families, communities, or society as a whole - from one of limitations to one of empowerment and possibility. We are dedicated to inspiring people and improving lives around the world, showing that there is beauty and hope in every circumstance.

The Brain Possible

The Brain Possible was created to inspire and empower parents, caregivers and practitioners who care for children with brain injuries. It is a project of The Who Is Carter Foundation, which was founded in 2017 to change the conversation around childhood brain injury from one of limitations to one of hope.

Kids Wish Network

Kids Wish Network is committed to infusing hope, creating happy memories and improving the quality of life for children experiencing life-altering situations.

Make A Wish Foundation

Make a Wish Foundation grants the wish of a child diagnosed with a life-threatening medical condition in the United States and its territories.

Pediatric Brain Tumor Foundation

With a mission to Care. Cure. Thrive., the Pediatric Brain Tumor Foundation leads the way in funding childhood brain cancer research to cure the kids, supports families affected by this disease and advocates for policies that help patients, survivors and their loved ones.

Variety, the Children's Charity

Variety, the Children's Charity provides financial assistance for families of special needs children in need of medical equipment/devices, physical therapy, educational resources, home renovation and more.

National AMBUCS, Inc.

National AMBUCS, Inc. creates mobility and independence for people with disabilities by providing therapeutic tricycles to individuals unable to operate a traditional bike.

The Shannon Foundation

The Shannon Foundation helps fund necessary medical care for children in need through hospital social workers.

UnitedHealthCare Children's Foundation

UnitedHealthCare Children's Foundation grants provide financial help/assistance for families with children that have medical needs not covered by their health insurance plan.

Holton's Heroes

Holton's Heroes provides support, information and rehabilitative devices for children and families affected by post-birth brain injury.

Ellie's Army Foundation

We are Ellie's Army, dedicated to providing children and young adults battling life-threatening illnesses with the possibility of a healthier future. By offering financial assistance and personalized support, we ease their families' stress and help ensure their best chance to survive.

Lori's Voice

Lori's Voice provides financial assistance for families with children under 21 who are unable to afford equipment, travel and therapy not [fully] covered by insurance or other organizations.

Chase's Warrior Foundation

Chase's Warrior Foundation provides families and local school districts with costly adaptive and therapeutic equipment.

Victoria's Victory Foundation

Victoria's Victory Foundation provides assistance with the day to day needs of those living with spinal cord injuries, traumatic brain injuries and other mobility related disabilities.

Cherished Creations

Cherished Creations fulfills dream requests for children with serious illnesses.

Chive Charities

Chive Charities provides funding for rare medical conditions, veterans with medical-related needs, first responders & emergency assistance organizations & underfunded special needs education initiatives

Small Steps in Speech

Small Steps in Speech provides grants to children with speech and language disorders for therapies, treatments and communicative devices.

Do It For The Love

Do It For The Love grants live concert wishes for people with life-threatening illnesses, children with severe challenges & wounded veterans.

Oracle Health Foundation

Oracle Health Foundation provides funding for children whose families cannot afford medical care equipment, vehicle modifications, or displacement related to care.

Granted Wish Foundation

Granted Wish Foundation provides sports/athlete specific wishes for people with a physical disability aged 5-25.

Children's Flight of Hope

Children's Flight of Hope provides flights to specialized medical care that might otherwise financially be out of reach.

PALS SkyHope

PALS SkyHope provides free medical flights to people who need to access medical care that may be too far to get to by car.

Mercy Medical Angels

Mercy Medical Angels provides assistance for transportation on the ground with gas cards, bus or train tickets, or in the air with flights flown by volunteer pilots or commercial airlines.

Project Angel Fares

Project Angel Fares provides all travel expenses paid trips to Morgan's Wonderland & Inspiration Island (fully accessible theme & water park) in San Antonio.

Miracle Flights

Provides free flights to those in need of life-changing medical care not available in their local communities.

National Organization for Vehicle Accessibility

NOVA provides small grants to help complete accessible van purchases after other funding has been secured.

Mclindon Family Foundation

Mclindon Family Foundation provides adaptive bikes to children with special needs to maximize their potential and participation in society.

Modest Needs

Modest Needs provides short term critical-need financial assistance for those who qualify.

The Sunshine Foundation

The Sunshine Foundation grants special dreams to children, ages 3-18, who are chronically or seriously ill, physically challenged or have been abused.

Wheelchairs 4 Kids

Wheelchairs 4 Kids provides wheelchairs, home & vehicle modifications, and devices for children with limited mobility.

Joshua Harr Shane Foundation

Joshua Harr Shane Foundation provides financial assistance for medical treatment, household bills, treatment and related expenses and financial aid for experimental treatments.

Ray Tye Medical Aid Foundation

Ray Tye Medical Aid Foundation provides grants for in-hospital lifesaving treatments and surgeries for those who do not have medical insurance.

My Gym Foundation

My Gym Foundation provides financial assistance of \$500 or less for children with disabilities.

Bryon Riesch Paralysis Foundation

Bryon Riech Paralysis Foundation provides charitable grants for assistive technology, devices, wheelchairs, modifications, equipment, computers, ramps, etc. for individuals with a neurological disorder with preference going to spinal cord injuries.

Special Kids Fund

Special Kids Fund provides modified vans for children with special needs.

Aubrey Rose Foundation

Aubrey Rose Foundation helps children with life-threatening illnesses with our focus being on the family unit. We strive to lift families from life's complexities during this difficult time by providing emotional and financial support.

Wheels of Happiness

Wheels of Happiness provides mobility aids, medical supplies, scholarships, psychological support, and fund lifechanging operations to underserved communities worldwide.

World Pediatrics

World Pediatrics deliver pediatric surgical and specialty care to children in need around the world.

Brain Injury Association of America

BIAA improves the quality of life of people affected by brain injury across their lifespan through advancing prevention, awareness, research, treatment, education, and advocacy.

Easter Seals

Easter Seals offers a variety of services to help people with disabilities address life's challenges from child development centers to physical rehabilitation and job training for people with disabilities.

The Special Needs Alliance

The Special Needs Alliance helps individuals with disabilities, their families and the professionals who serve them.

Family Voices

Family Voices is a national family-led organization of families and friends of children and youth with special health care needs (CYSHCN) and disabilities. We connect a network of family organizations across the United States that provide support to families of CYSHCN.

iHOPE

The international Academy of Hope is a highly specialized brain injury school in New York. The mission of iHope is to change the world for children, youth and young adults who suffer from brain injury and other brain-based disorders by improving services, training and research in this country and beyond.

Pediatric Brain Injury Web Resources

GENERAL INFORMATION

Team Luke Hope for Minds
teamlukehopeforminds.org/resources

Brain Injury Association of America
biausa.org/

United States Brain Injury Alliance
usbia.org

BrainLine
brainline.org/

Child Neurology Foundation
childneurologyfoundation.org

Children's Safety Network
childrenssafetynetwork.org

The Bart Foundation
thebartfoundation.org

Center on Brain Injury Trauma and Training
cbirt.org

Brain Trauma Foundation
braintrauma.org

Shepherd Center's Brain Injury (video series)
braininjury101.org

Center for Disease and Control
cdc.gov/traumatic-brain-injury

Institutes for Achievement of Human Potential
iahp.org/hurt-children/understanding-brain-injury

National Center of Health, Physical Activity,
and Disability
nchpad.org

National Institute of Neurological Disorders
and Stroke
ninds.nih.gov

National Rehabilitation Information Center
naric.com

National Resource Center for TBI
tbi.vcu.edu

National Organization for Rare Disorders
rarediseases.org

GOVERNMENT BENEFITS

Medicaid
medicaid.gov

Social Security Administration
ssa.gov

Kids Waivers
kidswaivers.org

Government Benefit Finder
benefits.gov

Administration for Community Living
acl.gov

EDUCATION

US Department of Education-IDEA
sites.ed.gov/idea/about-idea

Office of Special Education Programs
www2.ed.gov/about/offices/list/osers/osep/about.html

Office of Special Education and Rehabilitative Services
www2.ed.gov/about/offices/list/osers/index.html

Center for Parent Information and Resources
parentcenterhub.org

LIFESTYLE

Feed a Brain
feedabrain.com

TryMunity- TBI Social Network
trymunity.com

Love Your Brain
loveyourbrain.com

Rewire Neurons
rewireneurons.com

ADVOCACY

Americans with Disability Act
ada.gov/resources/disability-rights-guide

CAREGIVERS SUPPORT

Family Caregiver Alliance
caregiver.org/resource/traumatic-brain-injury

Care 4 the Caregivers
care4thecaregivers.org

Support Groups + Networks

FINDING SUPPORT GROUPS

Whatever the extent of your child's injuries may be, you need support! You don't have to carry the burden and stress of your situation alone. There are numerous organizations that seek to connect those affected by an acquired brain injury, and although pediatric support groups are not as numerous, there are still many groups that can offer support!

Parent 2 Parent USA offers an online manual on how to begin creating a Personal Support Network at their website: p2pusa.org/parents/

BIAA lists several adult support groups throughout the US and are worth exploring to see if they are a good fit for you and your child, located at this site: biausa.org/public-affairs/media/virtual-support-groups

Online Support Groups

While there are a many forums and resources online, it's important to be cautious and smart about information you may read online or advice you may be given from other parents or individuals online. Seek out websites or communities that are well monitored and provide positive support.

Team Luke Hope for Minds has virtual support groups for parents, caregivers and siblings of brain injured children. Please visit our website: bit.ly/_getsupport for support group details.

Trymunity (community.trymunity.com/) is an online community for survivors of brain injuries and supporters to provide an environment of positive influence and to strengthen each other to continue to fight through the obstacles and pain associated with acquired brain injuries.

Working with Service Providers



While in the Hospital



“GO WITH YOUR GUT”

Your child’s recovery begins the first day that he/she spends in the hospital. Although the hospital is staffed with professionals that have much more medical knowledge and experience, you as the parent are ultimately your child’s primary caregiver. You are also the best and perhaps the only advocate for your child. So, dismiss any feelings of helplessness or incompetence. Medical professionals are partners seeking the health of your child, but you are still your child’s “guardian.”

DECISIONS

Because the FDA states that “little can be done to reverse brain damage,” your child’s doctor may have a negative outlook concerning their recovery. It would be more accurate to state, “Many interventions can promote healing, because the brain has a limited ability to slowly repair and recover (plasticity) from injury. The brain however will likely only recover in small degrees, perhaps not significantly, and probably not totally.” If your child receives a devastating brain injury, hospital staff will intuitively and seriously consider requesting your consent/permission to collect their organs in order to transplant them into patients waiting for an organ donor. Some physicians will pressure you and others will just present the option of ‘letting your child go.’ Their experience has shown them that most patients do not significantly recover from severe brain injury (BI),

the patients require an extreme amount of effort to care for, have a drastically reduced quality of life, and produce exorbitantly high medical bills.

As a parent you are probably thinking, “I want my child alive at any cost, I am willing to do anything to give her a fighting chance. I will love them and will fight for them no matter what condition they’re in. Maybe they will be one of the ones that recovers.” Some children, despite all medical expectations, recover better than expected. One family was told that their child would pass away in a week and two years later their son is walking and talking. Conversely, there is a mother who is bitter towards hospital staff for resuscitating her child when they knew her ‘life’ would consist of laying year after year on a bed without the ability to move or communicate. Both options deserve serious deliberation. Make this decision when both time and assessments have demonstrated the condition of your child, you are better educated, and have had time to rest. Major decisions should not be made quickly or under pressure.

John, JD’s dad, comments, “My belief is this, doctors try their best to avoid false hope. I am not saying they should claim everything will be bright and rosy, what I am saying is they don’t know, so please, please give your child a chance, stick with them. For Beth and I, it was calling on our faith and knowing JD was counting on us to stand strong for him and give him a chance. Once

we accepted this commitment, our HOPE was further strengthened.”

INSURANCE & FINANCES

The sooner you understand what your insurance company will pay for, the better. Find out if your child qualifies for Supplemental Security Income, Medicaid, Medicaid Waiver programs, or support from the hospital’s business office. Begin the application processes for medical equipment through state and private resources once you know what your insurance will not cover. Get more details in the “Resources for Support” section of this Guide.

PREPARE TO TRANSITION FROM THE HOSPITAL TO YOUR HOME

1. Wheelchairs, ankle foot orthosis, and other devices may require measurement and special ordering. Once you know the funding source select a durable medical equipment company (DME provider) and begin the process. It is much easier to obtain recommendations from physicians when you are in the hospital and you see them face to face daily.
2. Research, interview and select a home nurse health provider so they can begin recruiting nurses to care for your child once you transition home.
3. Research, interview and select a provider of home health therapies such as physical, occupational and speech therapies.
4. If applicable, purchase a wheelchair accessible

vehicle. This may be a good focus for a community fundraiser. Your child’s head height while sitting in your selected wheelchair is an important consideration when choosing a van.

5. Organize and prepare your child’s room. Determine what equipment will be provided through insurance, which you will need to purchase, and what equipment you will request support purchasing. Some items such as beds and mattresses may be provided, but are low quality so you will want to upgrade. Read the “Equipment and Medical Devices” section of this guide for ideas.
6. Begin the process of enrolling your child in the school’s special education program. This begins with a call to the campus administrator in charge of the special education program and will progress through evaluations to a meeting that determines admission. The process can take half of a school year. See more information in the “Transitions and Support” section.
7. Learn from nurses and therapists how to care for your child before you transition home. Observe, take notes, video, and have nurses supervise you as you care for your child in the hospital. You must have the competence and confidence to take care of your child without the presence of a nurse.

Your Relationship with Medical Providers

Whether you like it or not, the professionals that provide medical service and support to your child are a crucial part of your child’s team. You are the boss! And like every supervisor, you have the ability to build good relationships and inspire excellent service. Your attitude and competence will contribute significantly to the quality of care and services that your child

receives.

Your child depends on you to influence service providers to provide good service. Be proactive and ask other parents for recommendations. Specialty clinics may have a waiting list and good doctors may be full. Like every other profession, there are great, average, and terrible providers in the medical service arena.

Once you intentionally choose your service providers, consider the following. Remember, it isn't a permanent decision.

DOCTORS

Doctors give a prognosis which is an estimate based on their education and experience of what is likely to happen, but not what can happen. You are your child's best advocate. Doctors are more willing to listen if your thoughts are backed by research or other medical authorities such as specialists. They are more likely to listen if you are logical, well informed, persistent, and determined. You should also be eager to listen to and learn from your doctor. You are a team, partner with them.

Prepare questions in advance and ask doctors for additional advice and recommendations on care and treatment. Your doctor prefers using data about your child so keep a record of dates, your child's conditions, reactions and reactions to drugs or treatments.

Present data to the doctor when you request changes. Learn why your doctor prescribes one medication over another or why a given equipment setting or medical order is given. If a doctor refuses a request, respond with, "What are you able to do?" Be firm with physicians but treat your doctor with respect and avoid insults or remarks that will ruin your relationship with any doctor. Keep in mind that even large hospitals have only a few neurologists and pulmonologists. They care about their relationship with other doctors, their employer (the hospital), and their professional license. You need their cooperation and remember that as the parent you may not always be right. If you are not comfortable with an assigned doctor, consider selecting a new physician or a new hospital after contacting other parents (through support groups) who can advise you on the best physician or treatment center to move to.

HOME HEALTH PROVIDERS

Home nurses can vary in their performance. Some providers have large pools of nurses to provide service but they may not be as particular when hiring. Other companies are more careful when hiring but have a

smaller pool and therefore less ability to meet your need for nursing support. When your child's home health provider hires your child's nurse, they may not be able to ask important questions such as, "Did this nurse do a good job?," "Why did this nurse leave?," or "Do you have any concerns about the quality of care that this nurse provides?" They can only ask, "Is this nurse available for rehire?" Home health nurses are in a desperately high demand and can stay employed for decades even if they are not great. Your job is to screen out bad nurses even if it means you won't have a nurse. Use your home health company's nurse supervisor and case manager to help you manage your nurses and know what skills they are expected to bring to your child's care.

RESOURCE FOR HOME HEALTH:

When you or someone you love needs home health care, you can find yourself facing a variety of unfamiliar situations and challenges. Written by a dad who was thrown into the home health care world when his ten-year-old daughter suffered a severe brain injury, *Strangers in Your Home* addresses the challenges from the perspective of someone who has been there. Ben Cockerham will help you navigate the system and help you have positive and professional relationships with home health providers. Personal and practical, the book examines:

- How to create a good partnership
- How to attract and hire good nurses
- Choosing a home health nursing agency
- How to prevent abuse or abandonment
- How to reduce nurse turnover and improve care
- How to create a professional work atmosphere
- How to prevent and resolve conflicts
- How to improve communication
- And more

Strangers in Your Home is available for free for all Team Luke Hope For Minds families at teamlukehopeforminds.org under "resources."

Caring for Your Child



Caring for Your Child

The day-to-day care of your child is an important factor in his/her condition and recovery. Caring for your child can seem like a daunting task, and you may feel overwhelmed, but again remember to remain hopeful and to accept help. You may feel alone but you are not! Numerous support services, agencies, and other routes of aid can be found in the “Resources for Support” section of the Guide. In addition, here are some helpful tips on daily aspects and things to be aware of in the care of your child.

WHILE YOU ARE IN THE HOSPITAL - BEGIN PROMOTING RECOVERY

- Conduct massages to assist in range of motion and decrease spasticity with the guidance of your care team.
- Talk & read to your child.
- Improve your child’s diet by speaking with the nutritionist about supplements and high quality food blends.
- Ensure that your child receives good oral care and receives care in accordance with a pneumonia prevention protocol.
- If your child experiences any unique event such as diarrhea or any medication or condition that contributes to dehydration, make sure extra fluids are provided.
- Monitor for skin breakdown or pressure sores that develop in uncommon places such as on the back of the head.
- Find out if your child qualifies for Supplemental Security Income, Medicaid, or support from the hospital’s business office.
- Begin the application processes for medical equipment through state and private resources once you know what your insurance will not cover.

John, father of JD Hartman says, “Love on your kid like never before, let them know you will be with them through this and how proud you are of them. JD was in a coma for over 6 months, through this time we continued to love on him, encourage him and stayed by his side. We saw him calm when we loved on him, even when his body was uncontrollable. Your child needs you more than ever and knows more than any medical evaluation will glean, give them HOPE with your love.”

INTERNAL CARE

Hydration

Inadequate water consumption can potentially impede your child’s recovery and condition. Be mindful of water consumption, although your nutritionist will prescribe an exact amount of water for your child, always be aware of changes in your child or her environment that may warrant additional liquid.

For instance, if your child experiences bouts of diarrhea, takes medication that dehydrates, goes through a period of excessive drooling, experiences fever or excessive urination, he/she may need supplemental water beyond the regular amount. Your nurse and dietitian can guide you to ensure that you do not provide excessive water which can be harmful as well. Keep in mind that excessive water consumption can lead to electrolyte imbalances which may lead to muscle spasms or cardiac problems.

Nutrition

Your child’s nutrition is vital to their health. Thus, educate yourself on what foods your child receives while in the hospital. If nutrition is through a feeding tube, investigate what is being fed to your child.

While in the hospital you may be provided with nutrition advice, but often these estimates focus only on caloric needs, generic fluid need, and vitamin intake. Factors such as fiber content, digestibility, amount of sugar, variety, or micro nutrient content may be missed. Some products consist primarily of water, sugar, and vitamins. Although these satisfy caloric needs for your child, make sure your child is getting food that is nutrient dense.

Consider asking your nutritionist to provide more substantial food that is similar to what your child

would eat at home. There are some options available like pre-packaged supplements.

Use a high quality blender to make more diverse meals and nutrients. You can purchase a discounted commercial grade blender via the Medical Hardship Discount Program.

DIGESTIVE AND BOWEL CARE

Regular bowel movements (BM) are a fundamental aspect of your child's health. Fecal matter is waste that the human body wants to get rid of. Constipation is physically uncomfortable and causes your child's body to hold onto toxins.

Probiotics

If your child's bowel movements are irregular or sparse, supplement food with probiotics into their diet. Probiotics are bacteria that improve the digestive process by breaking down digested food in the gut. If your child is on antibiotics, they may have a deficiency of probiotics. Consider supplementing probiotics through foods like yogurt, kefir or fermented products like sauerkraut or kimchi.

Juices

Additionally, there are several juices that may promote regular bowel movements.

Peach, plum, prune, and pear juices are high in sorbitol which pulls water into stools. Black currant, mulberry, blueberry, passion fruit, and aloe also promote bowel movements in some patients. Aronia berry juice just like cranberry juice has high amounts of quinic acid which may help to facilitate bowel movement.

Keep in mind that most juices are high in sugar which may cause weight gain.

Juiced vegetables are a high fiber low sugar option to consider integrating. Variety and attentiveness seem to be key factors in terms of diets that help to sustain a healthy gut.

Laxatives

It is important to consider that laxatives are not intended or approved for long term use. They can quickly make the bowel dependent on them. They may also interfere with the absorption of minerals, interact with other drugs, and

pull excessive amounts of water from the body. Although many laxatives are available over the counter, they can cause harm. Laxative use is a great topic to consult with your child's physician. Although it is important, keep in mind the effects may vary from person to person and not all laxatives may be the best for your child.

Physical activity can also help with bowel movements. Try to incorporate movement in a wheelchair or repositioning in a hospital bed.

Neurogenic Bowel Dysfunction

With neural injuries, it is common to see impairment of the bowels of those injured. When normal therapies like laxatives, diet changes or physical activity fail, the conditions of the individual are often referred to as Neurogenic Bowel Dysfunction.⁵

Neurostimulation is a potential therapy option for bowel difficulty when other methods fail (more information is located in the Therapies and Interventions section).

Therapies are mostly non-invasive and consist of peripheral electrical stimulation and magnetic stimulation

Notes on Stools

Bowel movement information is one of the key pieces of information that is passed as nurses transition from shift to shift. Consider keeping a personal journal to record and keep track of your child's bowel movements.

This will keep you organized, respectful of private information and allow more information to be logged. Stools are a window into your child's health, and doctors should be made aware of any drastic changes in stools.

EXTERNAL CARE

Preventing Pneumonia

If your child is being intubated, take precautions in order to prevent infections! Ventilator Associated Pneumonia (VAP) is one of the most common infections experienced by intubated patients³ and is the leading cause of death for minimally conscious and unresponsive wakeful (vegetative) patients¹¹ (multiple organ failure, infection, stroke, and embolism are the next leading causes of death).

Pneumonia is not prevented by one act but by a prevention protocol that involves several interventions

such as those listed in the Spanish ‘Zero-VAP’ bundle.¹² The Zero-VAP bundle consists of seven mandatory and three highly recommended interventions.

The mandatory interventions are education and training in airway management, strict hand hygiene for airway management, cuff pressure control, oral hygiene with chlorhexidine, semi-recumbent positioning, promoting measures that safely avoid or reduce time on ventilator, and discouraging scheduled changes of ventilator circuits, humidifiers and endotracheal tubes.

The three highly recommended measures are: selective decontamination of the digestive tract, aspiration of subglottic secretions, and a short course of IV antibiotics only if clinically needed.

Oral Care

Proper oral care is one of the most critical aspects of pneumonia prevention. Within the first 24 hours of entry into a hospital, patients may be exposed to dangerous bacteria, such as *Staphylococcus aureus* that colonize in mouth plaque.

In a controlled study of VAP, infection rate was reduced to 0% in groups that required nurses to brush patient’s teeth every 8 hours as one aspect of a pneumonia prevention protocol.

Although the mouth (depends on age of child) can be cleaned with antiseptics such as 1.5% hydrogen peroxide or 0.05% cetylpyridinium chloride,³ Chlorhexidine is recommended in VAP prevention guidelines.

Proper sanitation of anything that comes into contact with your child’s mouth can help prevent harmful infection. Make sure all items that enter your child’s mouth are properly sanitized such as suction devices, hands, and toothbrushes.

In addition to oral hygiene, make sure you, visitors and other people that come into contact with your child wash their hands properly. Ask them as they enter the room!

Eye Care

A vision therapist can assess your child’s ability to see and prescribe therapy to improve eye function. Some severely injured children may not be able to blink appropriately which can lead to severely dry eyes. Consider

performing eye soaks, eye drops or soft massaging of the eyelids.

As detailed in the Therapies and Interventions section, omega-3 fatty acids can also be supplemented in your child’s diet as they have been seen to improve the moisture of the eyes.

Doctors may typically prescribe petroleum based eye lubricants to protect the cornea. It is important to note that petroleum can lubricate and create a barrier, but it does not provide moisture to tissue despite its shiny appearance.

Lipid based moisturizers (such as fish oil) are also another route to help alleviate dryness in eyes.

Skin Care

Pressure sores are problems that can arise from prolonged immobility and they are caused by pressure, shear and moisture. Prevention of pressure injuries is 100% possible, but if untreated can become very harmful and even fatal.

Shear is the pulling of tissue as patients are moved or as they slide in a bed so be extremely careful when adjusting your child in bed. Pressure injuries are common on the backs of heels and buttocks but can occur under any bony parts of the body like the head, shoulder blades and hips. Some ways to prevent pressure injury include rotating your child at least once every 2 hours. A variety of rotation positions are okay, as long as they do not add stress to joints or the spine.

Bedding and accommodations are important aspects of skin care. The type of bed, fabrics and bedding your child uses can also help prevent sores and other pressure related conditions.

If your child has thick hair that hides the skin, ensure that the skin on the back of his/her head is routinely inspected for signs of a developing pressure sore. Remember to daily check for any possible signs of pressure. Early stages of pressure sores will appear as red, non-blanchable areas on the skin.

Choose mattresses and pillows that can optimize pressure and blood flow:

- Low air-loss mattresses have tiny holes that allow air to escape which reduces moisture and heat on the patient’s skin.

- The Hill-Rom Total Care bed is designed specifically for patients with brain injuries including features such as automatic rotation, a weight scale, and percussion therapy (for respiratory health)
- Medical grade sheepskin has been demonstrated to reduce the incidence of pressure ulcers and does not promote the buildup of heat or moisture.²
- High fiber pillows or foam can be purchased to support the patient and keep high risk areas protected.

In addition to the possibility of pressure sores, another area to focus on is the underarms in immobile patients. Buildup of moisture or friction from shirts can cause skin breakdown in an area that is not visible unless deliberate effort is made to inspect it.

Possible remedies to skin abrasions or abnormalities include mineral salt deodorant wipes or using silk or quick dry athletic shirts to reduce pressure and chafing instead of cotton or other thick clothing materials.

CONCURRENT ISSUES

With your child's brain injury there remains the chance it will be followed by other unexpected conditions, some of these conditions can be prevented or have their chances of occurrence lowered with proper daily care but some may inevitably arise, these include but are not limited to:

Epilepsy/Seizures

With a traumatic or severe brain injury, there is a growing incidence of patients developing epileptic like symptoms, referred to as post-traumatic epilepsy (PTE).⁶ Rates as high as 20-50% are reported. Consequently, it's imperative to be aware of the potential of seizures and epileptic symptoms, as well as how to prevent or treat them.⁷

In order to diagnose epileptic symptoms and PTE, it's important to understand what a seizure is. Some common signs of seizures are:⁷

- Strange movement of the head, body, arms, legs, or eyes, such as stiffening or shaking
- Unresponsiveness and staring
- Chewing, lip rhythmic smacking, or fumbling movements

- Strange smell, sound, feeling, taste, or visual images
- Sudden tiredness or dizziness
- Not being able to speak or understand others

As always, staying organized is key, and keeping a journal of any possible epileptic experiences can help diagnose and treat your child. Make sure to inform your healthcare professional of the information you've tracked to help them treat your child better. The usage of anti-epileptic drugs can help lessen the severity of seizures. Ask your healthcare professional about drugs they would suggest to treat or prevent any epileptic symptoms your child may develop.

Over Medication & Self Medication

Other conditions will and can arise, and it's easy to start your child on another drug for each condition. However, be mindful and cautious about the amount of drugs your child is on, as well as the side effects of each.

One important question to ask is, "Does my child absolutely need this medication?". While pharmacological products can benefit your child, always remember to ask about the side effects of all drugs and to make calculated decisions on what drugs your child takes. Do the potential negative side effects of this drug outweigh the need for this drug?

Additionally, if your child is able to self medicate, be aware that substance abuse is a real problem. Over reliance of medication and drugs often occurs without proper steps and preventative measures.

Spasticity

As defined by the American Association of Neurological Surgeons (AANS), spasticity refers to a state where muscles are continuously contracted. With a severe brain injury, the pathway between the nervous system and the muscles can be disrupted and thus result in abnormal and involuntary muscular activity.

To diagnose whether your child is experiencing spasticity, watch for signs like rigidly held elbows, clenched fists or bent wrists and/or fingers.

One of the most common treatments of spasticity is the usage of Baclofen, which can be taken orally or via liquid delivery to the spine by an intrathecal baclofen

pump (ITB).¹⁵ In cases of severe spasticity, ITB has been a popular method of treatment, and you may want to consult your doctor if ITB is something you want your child to receive. ITB has been shown to be more effective at treating spasticity due to the direct delivery to the spine.¹⁵ Dosing can be continuous and flexible, allowing ease of care, and the pump can be removed if needed.

As always, there are side effects to using an ITB, and it does require surgical placement of the pump in the spine. Many insurance companies do cover ITB, and choosing to use ITB can be a cost-effective option for spasticity treatment.¹⁵ Compared to other surgical treatments, ITB is reversible, as the pump can be stopped and removed if needed.

There are other different potential therapy and treatment options for spasticity that include:

- Physical, Occupational and Neurodevelopmental Therapy
- Botox Injections (BTA) are often used in acute, minimal amounts and have shown great promise
- Oral Medications (Benzodiazepines, Dantrolene sodium, Imidazolines, Gabapentin)

As always, be sure to first consult your healthcare professional and ask for their advice before pursuing any options or therapies.

Scoliosis

With spasticity and abnormal muscle contractions, the risk for scoliosis or abnormal spine curvature can also arise. Unfortunately, scoliosis is quite common with neural and spinal cord injuries.⁸

It is important to observe your child's spine conditions and to monitor or keep track of any abnormalities you see. If your child begins to develop scoliosis, some non-operative treatments include wearing a firm body brace molded to the upper body or modifications to wheelchairs that shape to your child's spine.

Certain surgeries are available for treatment, but often surgeries are reserved for spinal curvatures over 50 degrees. These surgeries usually involve placement of metal plates or implants that help straighten the spine. Again, consult your doctor before making any major surgical decisions or pursuing any treatment options!

Vision

Additionally, your child's sight can potentially be adversely affected because of their brain injury. Vision includes not only our eyes, but also our brain and visual cortex are extremely vital to how we perceive the world through sight.

Commonly reported problems in cases of acquired brain injuries include blurred or double vision, decreased peripheral vision, and frequent irritability or headaches from unfocused vision.

The severity and the visual aspects affected by brain injury will depend on the nature of your child's brain injury. It is important to pay attention to your child's complaints or any problems you may observe relating to visual deficiencies like the inability to maintain balance, to focus on objects or to search for objects visually.

If you have any suspicions or concerns about the condition of your child's vision, schedule an appointment with eye doctors, optometrists or other vision specialists. It is important to consider that although your child's eyes may not exhibit any apparent deficiencies, the problems associated with their vision will likely be caused by problems in the brain and visual cortex. You may want to consult neuro-optometrists or neuro-ophthalmologists who specialize with brain-related visual problems.

Ask for a Functional Vision Assessment (FVA) from your school district. The functional vision assessment is a pivotal assessment for children who have low vision. It is an assessment of how a child uses the vision he or she has in everyday life, so it is usually not done with children who are totally blind or have light perception only.

Possible therapies include the usage of corrective lenses which can help with problems focusing or scanning the visual field.

You may consider using prism glasses as well, which alter the way light hits the eyes. Prism glasses have shown promise in alleviating visual neglect in stroke patients, as well as concussions and other traumatic brain injuries.^{13,14}

As always, it's important to discuss any treatments with your doctor and to consult with vision specialists that have experience with brain-related injuries.

Caring for Yourself + Your Family



Caring for Others

YOURSELF

Your child needs an emotionally and physically healthy parent to take care of them! One mother, Liz's experiences detailed below demonstrate the importance of a positive caregiver.

Liz's son, Conrad, experienced a non-fatal drowning at the age of 17 months. Liz's insights and wisdom may be the most important component of this Guide.

"We can be a source of hope and inspiration to others when we are not victims. Our example can quietly encourage others. Allow this to become part of a normal life instead of taking over your life, or you can't attract the positive. You have to be the kind of person that can be helped. Friends and family support, you need them or you [can] get tired, overwhelmed and angry" advises Liz.

As your child's caregiver, you are one of the biggest sources of support and healing in their life. Therefore, you need to learn to care for yourself!

The stress and huge burden of your child's injury is not something you and your family have to carry alone. Although you may not want to feel like a burden or hassle to others in your life, learning to look past any such worries is necessary in order to ensure better care for your child in the long-term.

You will not have all the answers, solutions, and ideas to combat the difficulties that lie ahead. However, you play the most important role in your child's life as a source of love, affection and care. Your child needs you to be your best possible self, and that starts with you understanding to look after yourself and your family.

YOUR MARRIAGE

If you are in a marriage or committed relationship, you and your partner need to work together. Many marriages end in divorce after the unexpected disability of a child, with some reports citing rates of divorce as high as 70-80%¹. If you blame your spouse for your child's injury, you have to realize that the shoe could easily be on the other foot and you could

have been the parent "most to blame." You shouldn't blame and condemn yourself. Guilt and condemnation based on past mistakes will only make your present reality a nightmare. Would your child want you to blame yourself or your spouse, or would they want forgiveness?

With that in mind, it's important to understand the reality of your situation. First and foremost, learn to find strength from each other, and to not look at each other as the enemy. Arguments will happen, and they will be over every possible thing. However, it is vital to remember that at the end of the day, you and your spouse are working towards the same thing, the care and healing of your child.

Partaking in marriage counseling can be a way to learn to appreciate each other, and to work in unity. Stress from your child's injury will put a huge toll on your mind and spirit, so it is imperative to avoid adding other stress from disagreements with each other. Devoting time to each other may feel unnecessary or undeserved, but learn to set apart this time! Your marriage can be the backbone of your support, and thus, you need to nurture and maintain it as well.

YOUR OTHER CHILDREN

If your child has siblings, make time for them also! The time you must devote to your injured child will undoubtedly increase dramatically, but remember to spend quality time with your other children.

Chelsi McLain's brother suffered an anoxic brain injury after being hit by lightning when he was nine and she was thirteen years old. She is now a Licensed Professional Counselor. She wanted to share her thoughts with families. She comments, "I am incredibly sorry for the tragedy that you have just experienced. I know that the world is falling down around you. You are going through a lot and feeling so many different emotions, and that is okay. I know you do not believe me right now, but eventually you and your family will find a new normal. After any traumatic experience, it is important that you take the necessary time to process the tragedy that has happened to your family. Counseling is an effective way to process the trauma, explore the feelings of grief you are experiencing, and develop skills to manage the strain this situation has and will put on you and your family. As a family member, it may not seem that the trauma has occurred to you; however, you are certainly directly affected by such an event. It is important to know that when you are going to counseling, you are not doing it only for yourself, but for your loved ones, so that you can be a better source of support for your family."

Help them understand the situation and address the reality of the situation with them. Although you won't be able to do all the things you could prior to your child's injury, make every little moment count. Have meals together, take walks at night, learn to do the normal things you would have done if your child was never injured.

Consider seeking counseling for them as well. You may not think this is necessary, but often counseling may be just as necessary for your other children too.

Lastly, there are resources available to help assist your other children in coping with their siblings injury and also making sense of their feelings and emotions in light of all of the changes they are experiencing. These resources include:

Sibling Leadership Network

The Sibling Leadership Network (SLN) provides siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. www.siblingleadership.org

Sibling Support Project

The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.

www.siblingsupport.org

Team Luke Hope for Minds

Team Luke Hope for Minds offers a one-on-one and group sibling support program. We aim to foster a supportive space where siblings can share their unique journeys and find understanding. Each session is tailored to address individual needs and challenges, promoting a sense of belonging and empowerment.

Interventions + Therapies



Professional Therapies

The purpose of this section is to make you aware of potential therapies for brain injured children. We are not promoting the therapies. Always consult a medical expert before treatments and consider the potential benefits and risks of any therapy or intervention before implementing. Physical, Occupational, Neurodevelopmental and Speech/Language therapies are an effective way to help rehabilitate your child from any difficulties they experience because of their injury.

PHYSICAL THERAPY

“Physical therapists (PTs) are highly-educated, licensed health care professionals who can help patients reduce pain and improve or restore mobility - in many cases without expensive surgery and often reducing the need for long-term use of prescription medications and their side effects.” (American Physical Therapy Association, APTA)

OCCUPATIONAL THERAPY

“Occupational therapists and occupational therapy assistants help people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations). Common occupational therapy interventions include helping children with disabilities to participate fully in school and social situations, helping people recovering from injury to regain skills, and providing supports for older adults experiencing physical and cognitive changes.” (American Occupational Therapy Association, AOTA)

NEURODEVELOPMENTAL TREATMENT

Neurodevelopmental treatment is often used by physical, speech and occupational therapists with patients that have difficulty with motor movement because of neurological impairments from stroke, cerebral palsy and head injuries.

Therapy will often involve repeated practice with certain movements ensuring ease and enhancement with common motor tasks. Practice makes perfect, and repeated movements with neurodevelopmental therapy will make certain actions easier for patients. Without neurodevelopmental treatment, patients run the risk of developing a limited set of patterns that they will apply to many tasks.

Therapists trained in neurodevelopmental therapy have advanced training that allows them to evaluate and treat a number of motor problems related to neurological deficits, and help affected individuals learn to be more independent. A good neurodevelopmental therapist can be a part of a team of caregivers and providers focused on improving your child's health.

Laser Therapy

Laser and light therapy, also known as photobio-modulation and photoneuromodulation, has been extensively studied since the 1960s and has been proven to be a safe and extremely effective modality to increase healing and speed recovery from nearly all ailments. This is true because at the very core of what this therapy does is it delivers more energy to your cells so they can do their job more efficiently, whether it's healing or producing neurotransmitters.

Whole Body Vibration

Whole body vibration has been reported to help many facets of life such as balance and coordination, bone density, muscle tone, lymphatic drainage, gut function, and pain.

Vagus Nerve Rehab

Neuroscience has proven in various ways that the vagus nerve and the vagal system are connected to healing many parts of the brain and body. If this system is properly integrated and therapy is properly applied the benefits are far reaching and powerful.

SPEECH AND LANGUAGE THERAPY

“The speech-language pathologist (SLP) is defined as the professional who engages in professional practice in the areas of communication and swallowing across

the lifespan. Communication and swallowing are broad terms encompassing many facets of function. Communication includes speech production and fluency, language, cognition, voice, resonance, and hearing. Swallowing includes all aspects of swallowing, including related feeding behaviors.” (American Speech-Language-Hearing Association, ASHA)

A common misconception with speech-language pathologists (SLP) is that they are focused solely on speech. In reality, a SLP will likely evaluate cognitive-communication, swallowing abilities, and social communication skills. When working with TBI patients, SLP will often perform an initial evaluation of these skills, and develop a treatment program targeting areas for improvement.

Treatment programs will vary from patient to patient but will often focus on expanding a patient’s independence in day to day activities.

Plans will often follow a general path of first improving stimulation of the senses, and educating family how to interact with a TBI patient. With increased improvement, a SLP may focus on attention improvement and awareness of self. Continued progression may shift treatment to improving memory, strategizing ways to problem solve and reason as well as interacting in social settings.

Employment of specialized therapists can benefit your child immensely in any impairments they may experience post-injury. It is not known how long after injury evaluations that these therapies should begin, but the indication from research is that delays in these therapies have been “correlated with worse functional outcomes and decreased rehabilitation efficiency in children with severe TBI”.⁹ Conversely, a retrospective study of children admitted to an inpatient rehabilitation center observed that patients scored significantly higher in all functional skills upon discharge.¹⁰ Additionally, many insurances will cover speech, occupational and physical therapies, so these routes of care for your child should be highly considered.

SPEECH LANGUAGE PATHOLOGY SERVICES:

LSVT LOUD Program

- An effective speech treatment for individuals with Parkinson’s Disease (PD) and other neurological conditions.
- Improves vocal loudness by stimulating the muscles of the larynx and speech mechanism through a systematic hierarchy of exercises.
- Treatment not only stimulates the motor system but also incorporates sensory awareness training.
- Treatment is administered in about 16 sessions over 4 consecutive weeks.

Deep Pharyngeal Neuromuscular Stimulation (DPNS):

Use of frozen lemon glycerin swabs to stimulate specific sites within the oral cavity to address the following:

- Increase salivation for digestion and lubrication
- Improve lingual coordination for mastication, bolus (food or drink in the mouth) transfer.
- Restore pressure/thermal/taste sensory receptors on the tongue to elicit needed movement for mastication and bolus transfer.
- Improve palatal reflex for restoration of velopharyngeal closure and to maintain closure during each swallow to complete each swallow with appropriate cessation of respiration (eliminate inhalation during the swallow) and to eliminate aspiration risk.
- Increase laryngeal elevation/suprahyoid muscle strength to increase epiglottal range of motion to eliminate aspiration risk.
- Improve pharyngeal contractibility to propel food/liquid boluses to the esophagus.

Neuromuscular Electrical Stimulation (NMES):

- 3 different NMES devices: EMS-2C (Facial E-stim), Vital Stim (Pharyngeal Constriction and Laryngeal range of motion), and Intellistim (Suprahyoid Muscles for increased laryngeal elevation).
- Vital Stim and Intellistim are FDA approved.
- These devices are used simultaneously with DPNS or multiple devices at the same time (for e.g. facial e-stim placement with Vital Stim and Intellistim on Suprahyoidal muscles) for muscle re-education,

and to prevent disuse atrophy to address facial weakness or droop as well as laryngeal range of motion.

Myofascial Release:

- To increase buccinators (cheek), obicularis oris (lips), and neck muscle tone and range of motion.
- This modality is addressed to improve swallowing and speech production.

Modified Barium Swallow Study:

- We complete MBS studies on-site to assess swallowing difficulties. Patients will receive a DVD copy of the study for their personal medical record on the day of the study.

Other Therapies:

- Augmentative and Alternative Communication Therapy (AAC)
- Prompts for Restructuring Oral Motor Phonetic Targets PROMPT

NEUROFEEDBACK THERAPY

Neurofeedback is a mode of ‘biofeedback’ that is based on EEG data or electroencephalograms that relays electrical brain activity. An aim of neurofeedback is to train the brain to generate normal, functional brain wave patterns, and training includes monitoring of brain wave patterns and involves patient’s attention during abnormal wave patterns.²²

Training involves breaking an individual’s attention when abnormal wave patterns arise, which will ideally prevent further abnormal wave patterns.²² Neurofeedback has been shown to reduce the symptoms and difficulties involved in a plethora of conditions ranging from ADHD, OCD, epilepsy, PTSD and even autism.^{22,23,24,25} Additionally, clinics that use neurofeedback are required to have health-care degrees and are regulated by state law.²²

HYPERBARIC O₂ THERAPY

What is Hyperbaric Treatment?

Hyperbarics is a method of therapy utilizing air pressure and enriched oxygen environments to increase the

levels of oxygen in the circulatory system. Treatments usually involve hour-long sessions within a pressurized body chamber that takes ambient (or room) oxygen and saturates the chamber and ultimately the individual’s blood with oxygen. Hyperbarics has actually been around since 1622, gaining more modern usage in the 1800’s through the 1920’s.

Today, hyperbarics is widespread in its use. For example over 400 NFL players have personal hyperbaric chambers for post-workout recovery and concussion therapy. Hyperbaric chambers are also found in hospitals for use in carbon monoxide poisoning, diving accidents and head trauma. There are hundreds of uses for Hyperbarics in addition to 14 FDA approved usages.

Why choose Hyperbaric treatment?

Authors of an article in the Journal of Restorative Neurology and Neuroscience reported that, “HBO₂ was found to induce modest, but statistically significant improvement in memory, attention, and executive function”.⁷ Hyperbarics has been shown to stimulate neurogenesis (the birth of new brain cells) which could benefit cognitive performance and ability. Angiogenesis (the birth of new blood vessels) has been observed as well with hyperbaric treatment which can help muscle movements, especially when coupled with exercise.

ALTERG ANTI-GRAVITY THERAPY

What is AlterG anti-gravity therapy?

AlterG produces several products that function by placing patients in a reduced gravitational environment, allowing patients to rehabilitate muscles that they otherwise could not.

Why use AlterG therapy?

AlterG has been shown to improve muscularity and movement in a number of conditions ranging from sports injuries to improving the muscles of stroke patients or those with neurological impairments of voluntary muscle movement.

Numerous studies have shown the positive impact

of AlterG on heart health, muscular dystrophy and stroke recovery, providing real signs of recovery and improvement in these cases.^{39, 40}

NUTRITION BASED THERAPIES

Fish Oil (DHA and EPA)

DHA and EPA in the form of fish oil pills are a common dietary supplement that contains long-unsaturated fatty acid chains that can benefit brain function.⁴ Specifically, the omega-3 fatty acids found in many fish oil pills have been shown to improve spinal cord and brain injuries in animal models.⁵ The forms used in a therapeutic trial involving a teenager in a vehicular accident were 15 ml twice a day (30 ml/day) providing 9,756 mg Eicosapentaenoic Acid (EPA), 6,756 mg Docosahexaenoic Acid (DHA), and 19,212 mg total n-3FA, and the patient saw gradual physical and cognitive benefits.⁶

DHA and EPA can also be a benefit to vision! In one study of contact lens wearers suffering from dry eyes, those who took 600 mg of omega-3 fatty acids (EPA and DHA) reported a decrease in symptoms.³⁸ In a study using mice, researchers determined that directly applying drops of fish oil and hyaluronic acid (used in many OTC eye drops) produced a significantly better improvement in corneal conditions and inflammation.

Melatonin

Melatonin is a hormone with powerful antioxidant effects. It is produced in multiple parts of the body and affects nearly every cell in the body on a regular basis.¹ After ischemic brain injury/stroke, melatonin has shown the ability to reduce infarct volume and/or inhibit neuronal cell death in different experimental models.² Melatonin has been shown to reduce cell damage by supporting the cell membrane in oxidative stressed cells.³ Melatonin has been shown to reduce pain, promote healing, and reduce the size of brain bruises (contusions) following TBI.

Melatonin has low toxicity, crosses the blood brain barrier and is considered relatively safe for administration for babies.² Melatonin is an important hormone in maintaining the body's health. TBI patients produce less melatonin so supplementation of melatonin can be

a form of therapy.

TOUCH AND SKIN THERAPIES

Massage Therapy

Massage Therapy improves blood flow and reduces pain. Increased awareness was observed in brain injured patients who received foot massage for five minutes on each foot daily compared with control patients.^{11,12}

Craniosacral Therapy

Craniosacral Therapy is a specific massage technique focused on the neck and head area. In a single case study it was shown to complement recovery.¹³ Massage techniques focused on the highest neck joint (atlas-to-occipital) and lymphatic drainage are recommended by some practitioners.¹⁴

Massage therapy is a branch of physical therapy and is covered by some insurance providers (including Medicaid). When you choose a company to provide therapy services, consider companies that can provide physical therapists licensed in massage. In one UK study, massage was the most commonly used 'alternative' therapy by parents with brain injured children.¹⁵

Other Treatments

- Acupuncture
- Essential Oil Aromatherapy, such as Frankincense

ELECTRICAL STIMULATION THERAPY

Deep Brain Stimulation (DBS)

DBS involves a surgically implanted neurotransmitter in the patient in order to deliver electrical pulses to the thalamus. It is an FDA approved therapy for treating Parkinson's Disease and dystonia. The limited number of clinical trials of DBS for TBI and MCS has shown improvements in a minority of patients although some improvements have been significant.^{26,27}

Repetitive Transcranial Magnetic Stimulation (rTMS)

rTMS involves small electrical currents produced by a coil which is held above a patient's head.

Practitioners have theorized that the alternating electrical current regulates damaged neurons.³² Low frequency rTMS have been shown to reduce symptoms of depression in patients with TBI³². A 2016 study involved 30 patients who had suffered a stroke, and patients who received actual TMS therapy showed significantly higher gains in upper body control and spatial neglect³³.

Other Treatments

- Left dorsolateral prefrontal cortex transcranial direct current stimulation (DLPF-tDCS)
- Neuromuscular Electrical Stimulation (NMES)

DRUG-BASED THERAPIES

When placing your child on medications, make sure you know exactly what possible side effects there are. If your child is taking multiple medications concurrently, make sure you consult your physician about any possible effects of taking multiple medications at the same time.

Dopaminergic Agents

Dopaminergics are chemicals that increase dopamine related activity in the brain. Dopamine is an important chemical involved in motor control pathways in the brain. Dopamine helps humans to have smooth, coordinated muscle movements.¹⁶ Patients that have trouble with involuntary movements or spasticity could benefit from dopaminergic drugs.

Levodopa

Levodopa has an established history treating Parkinson's disease and TBI for over 40 years and is considered the most effective medication available for the treatment of the motor symptoms.¹⁶ In a study involving TBI patients in a minimally conscious state. "After 2 to 5 months of administration of L-dopa/carbidopa; 4 patients (4 = 36.4%) showed significant clinical improvement".¹⁷

Apomorphine

Apomorphine is a drug used to treat patients with Parkinson's Disease and acts by activating dopamine

receptors. Its use in treating patients with TBI is recent and limited, but some trials have produced shockingly positive results. In a 2010 study, 8 minimally conscious patients were treated with Apomorphine, and 7 of the 8 patients regained consciousness within only 4 weeks of treatments, and improvements were sustained for over a year even after discontinuation of drug administration.¹⁸

Amantadine

Amantadine improved the rate of recovery and outcomes based on the Disability Rating Scale (DRS) during a trial of 184 patients who had experienced a TBI. All patients in the trial still had severe disability following the six week trial but treated patients were less likely to present in a vegetative state and scored slightly better on the DRS.¹⁹

Zolpidem/Ambien

Both Zolpidem and Ambien are sedatives used to treat insomnia in adults. Their sedative effects have been shown in a small percentage of cases to increase arousal and even 'awaken' patients in minimally conscious and vegetative states.^{20, 21} Ambien is thought to cause this paradoxical improvement by inhibiting the pallidum which in some brain damaged patients oversuppresses the thalamus and cortex.

Nuedexta

Nuedexta is the trade name for a combination of the drugs Dextromethorphan and quinidine. Nuedexta is used to treat pseudobulbar affect (PBA) which is sporadic and unpredictable laughing or crying episodes. PBA is a potential side effect of TBI.

MISCELLANEOUS THERAPIES

The Universal Exercise Unit (SUIT Therapy)

Or body weight support system - is comprised of a three-sided wire device, waist belt and bungee cords. The cords are specifically angled from the wire device to the child's waist belt to help position them in an upright position to perform balance and strengthening exercises that they would otherwise be unable to perform. Weight bearing is important for joint,

muscle, and bone health and the upright position also improves respiration, digestion, circulation, and bowel/bladder function. However, some children are unable to tolerate their full body weight without compromising proper positioning and alignment for safety in a standing position. The added security from the belt and bungees can assist with the child's balance so that the therapist can decrease their hands on support. This allows for the child to experience functional transitions from sitting to standing or floor to standing with less support. In turn this builds self-confidence and independence. As strength increases, support can be adjusted or taken away to continue progress towards more challenging activities and independence.

Ludo Therapy (Play Therapy)

A form of therapy involving usage of play situations to stimulate and aid children in recovery from neuronal, physical and cognitive injuries. Often, rehabilitation can be so focused on every nuance other than living a normal life. Remembering to play with your child just as you would if they had not suffered an injury can be as helpful as other therapies.

Neurostimulation

When dealing with a neuronal injury, many patients may unfortunately experience difficulties passing bowel movements. Initial treatments for bowel movement difficulties include laxatives and diet changes like increased fiber and probiotics, but when these methods don't improve your child's condition, you may consider neurostimulation. Neurostimulation involves sacral anterior root stimulation (SARS), sacral nerve stimulation (SNS), peripheral nerve stimulation, magnetic stimulation, and nerve re-routing, and in small-scale studies these therapies have shown promise in alleviating neural bowel disorder symptoms.³⁶ However, these therapies are still experimental, and require research and larger-scale studies, but they do hold promise.

Percutaneous Muscle Lengthening (PERCS), also known as Selective Percutaneous Myofascial Lengthening (SPML):

PERCS muscle lengthening is a great option to

consider when dealing with abnormal posture, motor deficits or gait/walking difficulties involved with your child's brain damage. This procedure is minimally invasive and is geared to managing contractures that are a result of brain injuries. Since many brain injuries leave children with abnormal posture or rigidity, PERCS is a very wise option when compared to other standard procedures geared at remedying contraction problems with muscles.

Stem Cell Therapy

Stem Cell Therapy collects unspecialized cells from patients, re-injecting them into the patients in damaged areas and contribute to repair. The benefits are more pronounced when administered during the acute phase of injury (7 days).²⁸ Studies show that the collection of bone marrow and infusion of bone marrow mononuclear cells to treat severe TBI in children is safe.²⁹ Data indicates that cell therapies help brain injured patients by reducing inflammation and necrotic areas, reduction of intracranial pressure, and enhancing the internal repair processes such as neovascularization which involves sprouting of blood vessels from preexisting ones.³⁰

Stem cell therapy in the United States is slowly progressing, with research shifting from minor experiments to large clinical trials. The FDA recognizes stem cell therapy for the treatment of some blood cancers and immune disorders.³¹ Currently, stem cell therapy is only FDA approved for bone marrow transplants.³³ Stem cell therapy is more widespread internationally, and there may be more options abroad for stem cell therapy.

Vision Therapy

Vision therapy is essentially physical therapy for the eyes. Vision problems are often overlooked with brain injuries, but vision-focused rehabilitation can benefit overall recovery. Almost 90% of patients with traumatic brain injuries exhibit some type of oculomotor deficit, which shows the prevalence of visual effects in brain injuries.³⁶ Therapy often begins with an initial consultation which is followed by a test of the health and function of the eyes. During testing, vision

therapists are able to determine if non-verbal patients can see. Following testing, therapists develop exercises to help improve the functioning of the eyes. Therapy is typically conducted 1-2 times a week in clinic in combination with exercises completed at home.

Although a growing number of insurance companies cover vision therapy, a large number of patients are forced to cover costs out of pocket. However, vision therapists often offer complimentary consultations in person or over the phone in order for you to learn about their services and how it could benefit your loved one.

Other Treatments

- Equine-assisted activities and therapies (EAAT)
- Aquatic Therapy
- Music Therapy
- Familiar Auditory Sensory Training (FAST)
- Lokomat
- Trexo Robotics
- VSEL
- Biocharger
- Neurosage by SNA Biotech

Equipment + Medical Devices



Home Medical Equipment + DME

Medical Equipment used at home is referred to as ‘durable medical equipment’ (DME) because it is operated by non-professionals and without regular maintenance.

In order to receive DME, your physician must complete forms from your DME provider stating the medical need for the equipment. Your DME provider will then request that your insurance company pay for the equipment.

The case manager should assist you with this process while in the hospital or during rehabilitation.

Just because there is a verified medical need does not guarantee that your insurance company will pay for the equipment. The process of obtaining equipment may require you to continually check to ensure that each step is moving along. As the parent, you may have to verify that each step is completed. If the DME provider tells you that they, “sent a fax to the physician last week,” verify that the fax was actually received and then made it to the appropriate recipients. Always double check and follow the steps below when trying to obtain DME.

PROCESS OF OBTAINING DME

1. Recognize the need for DME.
2. Inform your DME provider to send a request form to your physician to confirm a medical need.
3. Have your physician complete and return the necessary forms to the DME provider.
4. Have your DME provider send the requests to your insurance company.
5. Confirm your Insurance company authorizes and provides funds to the DME provider.

HOW TO OBTAIN FUNDING FOR DME

If insurance or SSI are not available to pay for DME, consider applying for aid through non-profit organizations such as those listed in the resource section of this Guide.

The resource section of this Guide does not include every potential source of financial aid. There are additional local, state, and national organizations that can assist you.

In addition, consider holding fundraisers. Small fundraisers like bake sales or large-scale events within your community are proactive ways to find funding for

DME. Other crowd-funding options through online portals like GoFundMe, GiveForward or **gogetfund ing**, are other creative ways to finance your child’s care.

TYPES OF DME

Wheelchairs

Your insurance company should provide a wheelchair if needed. A specialist will measure and order a wheelchair specifically for your child. However, this process of approval, measurement, and production of the chair can take several months. Instead of waiting months to receive a custom chair, consider purchasing a temporary wheelchair. Inexpensive chairs are often available from online forums such as Craigslist or from used equipment providers. Wheelchairs can also be rented if preferred. Custom built wheelchairs are likely to cost over \$5,000 and your insurance company may only ever provide one so it is important for you to provide input in order to ensure that the wheelchair for your child meet not only your child’s size but also the environment and needs of your child. For instance, if you plan on taking your child on frequent walks consider a chair with offroad tires, if the path is rough consider a wheelchair with shocks, if your wheelchair vehicle has a low roof ensure that the chair height is compatible. If your child lacks control of her neck and head ensure that the headrest has sides. If your home has narrow doorways or passages, consider the width of the chair. If you use a temporary chair you will have time to shop and to learn what your needs are before you purchase your final chair.

AFO (Ankle Foot Orthosis)

An AFO is a brace that goes around the foot and ankle designed to reduce the chances of foot drop. A specially tailored pair requires measurement and ordering so consider starting this process in the hospital.

IPV (Intrapulmonary Percussive Device)

An IPV is designed to loosen retained secretions in your child’s lungs by rapidly pulsing bursts of air through the mouth. The IPV or Cough Assist may be uncomfortable for your child. If possible, try them both out before purchasing one.

Cough Assist

A Cough Assist can help to clear retained secretions in your child's lungs which reduces the chances of pneumonia. Your insurance will likely not provide both a cough assist and IPV.

Mattresses

Air filled mattresses with features such as alternating pressure and/or a low air loss system are frequently used to assist with the prevention of bedsores. Air mattresses have extensive seams and use a motor that runs frequently; quality is therefore important. Some parents advise that, "You get what you pay for" in respect to medical mattresses. American made blowers and mattresses are viewed by some parents as more reliable. Invacare is a brand selected by some parents. Foam mattresses are used by some parents and hospitals. Foam mattresses were shown to lose 40% of their stiffness after 24 months of use.

Standers

Standers are frames that hold your child in a 'standing' position. Your child needs to stand because weightbearing increases bone strength, helps with bowel movements, and allows hip and knee flexors the opportunity to stretch. Some parents report that their children enjoy the chance to get in the standing position.

Walkers

Walkers are a useful aid to assist with mobility. In addition to the classic aluminum frame (often seen with tennis balls on the back pads, rollators are wheeled walkers that use handbrakes to control momentum.

Ventilator and Circuit

Ensure that if your child breathes through a ventilator that the air circuit (tube) is equipped with an internal heated wire. Many patients only receive the heated chamber and the air circuit with the water trap (cup) that collects condensation.

In addition to a very informative education section in their website: (<https://www.fphcare.com/respiratory/adult-and-pediatric-care/respiratory-care-continuum/humidity-defined/>), the respiratory experts at Fisher and Paykel can answer product and general questions via

phone. According to their website, the optimal temperature for inhaled gas is 37° C (98.7° F) at 100% humidity. Proper heating of the air that your child inhales prevents cooling of the brain. Non heated circuits may not be able to provide this temperature or humidity. Non heated circuits create more condensation and therefore require much more dumping of water from the trap and adding water to the heating chamber.

Pulse-Ox (Pulse Oximeter)

Pulse-Ox reads heart rate and blood oxygen content of your child. Learn how to lock the setting of your pulse-ox to ensure the alarm settings to not erase every time the device is unplugged. Consider purchasing a small portable Pulse-Ox to use when traveling or in a wheelchair. There are models that record and store your child's vitals which will provide better insight into their state. You can review your child's heart rate to check for reaction to medications, meals, or care in general. You can also review your child's recorded heart rate to check her condition during night shifts or times when you are not with your child. Some models even send email alerts when your child's heart rate rises above a determined setting.

Eye Tracking

Eye devices enable some disabled children to communicate by measuring very subtle eye movements.

Wheelchair Swings

Wheelchair Swings have a platform that supports and hold the wheelchair so your child can gently swing.

Wheelchair Van

There are multiple types of lifts, some lifts are split into a left and right section allowing people to enter and exit the van without having to raise and lower the lift. Converting a van with a lift and tie down straps is very expensive. Used vans are often available and insurance may subsidize the cost.

Miscellaneous Devices + Supplies

- Stethoscopes, thermometers, and flashlights will allow you to monitor your child's condition especially when home health nurses are not available.
- Silk or quick dry athletic shirts produce less friction on your child's back than a cotton shirt.
- Sheepskin pads can replace plastic chucks and large wool underlays can cover the entire bed. They reduce heat and moisture build up and have been shown to reduce pressure sores.
- Adjustable Tablet PC mounts will allow you to position a tablet screen so that your immobile child can view it.
- Portable Air Conditioners will compensate for the excessive heat created by the equipment in the room and improve circulation.
- Backup generators provide power during emergency outages.
- Essential oil diffusers improve the atmosphere and smell of your child's room and can be used during massage therapy, but may not be appropriate for all children.
- Air purifiers can remove contaminants such as dust and pollen from a room.
- Patient lift or ceiling track systems enable immobile patients the ability to transition from their bed.
- Portable Suction Machines are used for respiratory therapy or care.
- Wireless cameras help ensure the safety and care of your child during sleep or while you are away from the home.

Transitions + Support



Education

HOMEBOUND SERVICES

The school district of your child is required to provide a 'Fair and Appropriate' education to all children including your brain injured child. Every school has an administrator that is responsible for the campus' special education program (SPED). Your child will need an official assessment from the school before enrolling in the SPED program. The school's assessment for SPED services will be more accurate if you provide descriptive notes from your child's doctor that describes fully your child's condition. (Your doctor's notes should have descriptions such as "the child needs: frequent breaks, is alert sporadically, needs "x" medication with food, needs supervision at all times, experiences waves of fatigue," etc.).

If your child is unable to physically go to school, your school must send a teacher or therapists (when appropriate) to provide education support to your home. It is important to remember that your child's school district will only provide therapies if they directly correspond to your child's access to education. Also, your school district does not provide medical support. Home nurses can accompany your child to school to provide medical care. Some school districts



have specific campuses that are staffed to support children with complex medical problems.

HOME SCHOOLED + PRIVATE SCHOOLED CHILDREN

Your child can receive services delivered through public schools through federal guidelines called 'proportionate share'. Under the provisions for the Individuals with Disabilities Education Act (IDEA), districts receive limited funds in proportion to the number of disabled children that reside in their district but are not enrolled in public school. The school district you reside in should have funds specifically for your home-schooled child. In order to benefit from the IDEA, make sure you submit a written request to your school district, and once you have submitted your request, the school district is required to respond.

Don't limit your child's education! A special education teacher recommended that despite your child's brain injury, education should not be restricted to lower elementary level activities. For example, don't spend year after year reading your child the 'ABCs' or 'Brown Bear Brown Bear'. There are several reasons to include more challenging education even if your child doesn't retain or understand every aspect of it. For instance, your child may have higher cognition than you realize, and like a muscle the brain grows as it is challenged. It is productive for you and teachers to keep your child's interests and personality prior to injury in mind when you teach. If your child loved horses or a certain type of music prior to injury, integrate those topics into math, reading, and other therapies. For instance, math could involve word problems with horses or ranching, or the music theme to a western TV show could accompany physical therapy.

Special education teachers can integrate music, play, touch, and games in combination with adaptive technology such as switches that activate by head movement, large button switches, or personal digital assistants (PDAs) that are designed to provide accessibility to disabled children.

Transitioning to Adulthood



John Hartman, JD, and Ronda Johnson

Although your child is still legally under your care, it's important to plan for the future and to take precautions in case something were to happen to you. One crucial period in your child's life is when they turn 18.

GUARDIANSHIP

"The legal tool for becoming the spokesperson and decision maker for someone who is not able to exercise their own legal rights and responsibilities after age 18." If guardianship is obtained, certain rights and privileges are removed from your child and handed to the guardian, and cases of guardianship usually occur when an individual (your child) cannot provide food, clothing or shelter for themselves, care for their physical health, or manage their financial affairs.

HOW DO I OBTAIN GUARDIANSHIP?

To get guardianship of your child, you will need to go before the probate court of your county and petition to become your child's guardian. You will usually

have an attorney representing your interests, and your child's interest. The judge can rule that your child needs full guardianship or limited guardianship, an agreement that specifies areas where your child retains his or her rights. Guardianship must be renewed each year and you must also pay a bond each year to retain guardianship."

ALTERNATIVES TO GUARDIANSHIP

Several alternatives to guardianship are available: Power of Attorney, Durable Power of Attorney, Durable Power of Attorney over Health Care, Directive to Physician, Social Security Representative Payment Program and Trust.

In Conclusion

We hope that this guide is helpful to you and your family. It was created through contributions from many families, medical experts, and advisors. Team Luke Hope for Minds would like to thank Ben Cockerham, father of Evelyn, who suffered an anoxic brain injury after being struck by lightning, for his hours and hours of research and writing of the guide. Thanks also to Jeremiah Ling, an intern with Team Luke Hope for Minds, who co-authored, researched, and edited large sections of the guide.

Please remember that the goal of the guide is to share information about head injuries and brain

damage. It is not our intent to offer any medical opinions, assessments, or advice whatsoever. Please filter information from this guide through your child's doctors and specialists. This guide is a working document! If you have any suggestions or recommendations, you are encouraged to provide your input to info@teamlukehopeforminds.org.

Above all, may you be encouraged with the knowledge that through support, education, and continued love your child can make strides in his/her recovery.

‘ For Evelyn Pearl Cockerham and all of the other beautiful children that have had their lives tragically changed by an acquired brain injury. ’

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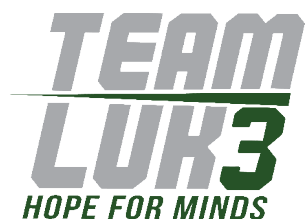
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Team Luke Hope for Minds

5701 W Slaughter Lane A130-324

Austin, Texas 78749

512 845-1466

info@teamlukehopeforminds.org