A PRACTICAL GUIDE FOR FAMILIES

Understanding a Child's Brain Injury Journey

BRAIN INJURY ASSOCIATION OF AMERICA

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OF AMERICA

About the Brain Injury Association of America

As the voice of brain injury, the mission of the Brain Injury Association of America (BIAA) is to improve the quality of life of people affected by brain injury across their lifespan through advancing prevention, awareness, research, treatment, education, and advocacy.

We are grateful to the many caregivers and survivors who shared their stories, experiences, and insights that inspired development of the first-ever pediatric version of this guide. Throughout the guide, you'll find quotes from real caregivers and survivors who share tips, advice, and words of encouragement from their own lived experience. We would also like to thank the expert contributors who developed the *Moderate to Severe Brain Injury: A Practical Guide for Families*, which laid the groundwork for this guide. Finally, we want to share our appreciation for the following individuals for their guidance on the content in this guide, as well as the countless ways they are working to improve the lives of survivors of brain injury every day.

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> "People with brain injuries need organizations like BIAA to help them navigate a new world, to help them understand why the world around them (and sometimes their own selves) suddenly seems so unfamiliar."
>
> Deborah Einhorn,
> Brain injury survivor and advocate

Disclaimer: The Brain Injury Association of America, Inc. (hereafter BIAA) created this guide as a service to those in need of brain injury information, treatment, and other services and support. The information provided is not a substitute for medical or professional care. Questions about diagnosis and treatment for brain injury should be directed to a physician or other healthcare provider. BIAA and its affiliates do not endorse, recommend, or guarantee any treatments, services, or service providers and are not liable or responsible for any claim, losses, or damages resulting from use of the information contained in this guide. The content is believed to be accurate but is not guaranteed. All content is provided "as is" without any warranty, expressed or implied. BIAA and its affiliates disclaim liability for any errors or omissions and disclaim any implied warranty or representation of accuracy or completeness.

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We are here to help you with your journey

We understand that the brain injury journey involves not just survivors, but also their family and friends. For this reason, this guide was lovingly put together by medical professionals, families, and survivors of brain injury. It was created for people caring for loved ones who were hospitalized for a brain injury or who are experiencing the effects of a brain injury.

Everyone's experience will be unique. Our hope is that this information will help you navigate your journey as you care for a loved one after a brain injury. We encourage you to take your time while reading this guide and to take notes along the way. We've included key takeaways for each section, as well as handouts and checklists that you can use on your journey.

You may be wondering…

Will my child get better?

The brain injury journey is different for each child, and there are many unknowns. But the good news is that many children living with brain injury will begin to feel better and regain many abilities they lost over time. Learn more about what researchers know about health outcomes after a brain injury on page 12.

How will we afford my child's care?

Brain injury care can be expensive and navigating the insurance process may be frustrating. Taking time off of work and paying for medications can also lead to financial stress on families. Check out page 25 for information on managing medical costs and financial support for families. See page 66 for a list of programs that offer free or discounted medications.

Where can I find a medical professional who specializes in brain injury?

Getting the right care is key. See pages 35-36 for information on neuro-resource facilitation (a program that helps link people to brain injury care), as well as how to find a Brain Injury Medicine-certified physician and to get a list of specialists who care for children with brain injury.

Connect with BIAA

It is normal to feel lost, confused, and overwhelmed during the brain injury journey. We are here to help. **Call BIAA's National Brain Injury Information Center at 1-800-444-6443** (Monday to Friday, 9 a.m. to 5 p.m. Eastern Time) to get confidential, personalized assistance and information on brain injury care, community services, and financial and legal resources. You can also visit us anytime online at www.biausa.org.

Checklist:

Starting the brain injury journey

☐ Get a binder or create a file on your computer to collect and keep medical documentation and records for hospital and medical visits.

☐ Review your child's insurance coverage and benefits. If you plan to apply for Medicaid or other state support, start the process right away. Getting enrolled takes time and can be challenging. See page 65 for more information on how to apply for Medicaid.

☐ Consider getting legal and financial advice on issues such as:

- Guardianship or supported decision-making.
- Power of attorney (medical and financial).
- Special needs trusts.
- ABLE (Achieving Better Life Experience) accounts.

See page 69 to learn more about these and other legal and financial considerations.

☐ Ask your employer about the availability of leave through the Family Medical Leave Act (FMLA) if you need to take time off work to provide care for your child. FMLA provides unpaid, job-protected leave. FMLA leave may be taken all at once or as needed during your child's brain injury journey.

☐ If your child was injured while at work, be sure that the employer is notified and that there is written documentation of the injury (such as how it happened and any witness reports). See page 68 for more information on what to do if your child is injured at work.

☐ Take time for yourself. Being a caregiver is hard. Consider:

- Asking for help from others so that you can have time for yourself.
- Creating weekly self-care goals, such as one hour of time for yourself with your phone on silent.

See pages 57-59 for more self- and family-care tips.

> *"…Caregivers, you are doing great work that may never get the highest recognition, but we know you are there and [we] are with you."*

What's included in this guide

Chapter 1: A child's brain and brain injury 7

To get involved in improving care for people living with brain injury, we encourage you to contact one of the Brain Injury Association of America state chapters or affiliates. You can find your state's chapter or affiliate at **www.biausa.org/find-bia.**

If you don't have a chapter or affiliate in your state, don't worry, we have you covered. You can get involved with us by going to **www.biausa.org**.

Mapping your journey

Each person's recovery path will be unique, and it likely won't follow a straight line. Your child may be admitted, discharged, and re-admitted to different hospitals, rehabilitation facilities, and programs along their journey. Here are a few possible stops along the way that you may encounter.

Emergency/Critical Care

(Emergency department)

Stabilize the patient

Prevent medical complications

Acute Rehabilitation

(Hospital)

Inpatient skilled rehabilitative care to improve function

Acute Care

(Hospital)

Medical care

Diagnostic tests

Development of a care plan

Subacute Rehabilitation

(Hospital, skilled nursing facility)

Complex nursing care

Less intensive rehabilitation to improve medical stability

Post-acute Rehabilitation

(Transitional/residential rehabilitation facility, day treatment program, home)

Improve independent living skills

Specialized Rehabilitation

(Neurobehavioral unit, substance use disorder treatment program)

Assistance with behavioral challenges

Management of substance use disorders

Home- and Community-based Care

Family support

Improve independent living skills

Chapter 1

A child's brain and brain injury

How the brain works

Our brain makes it possible for us to learn and remember, as well as do things that we often don't think about, like breathing and moving our arms and legs to walk and stand up. How we feel and our ability to see, hear, taste, smell, and sense touch are also controlled by our brain.

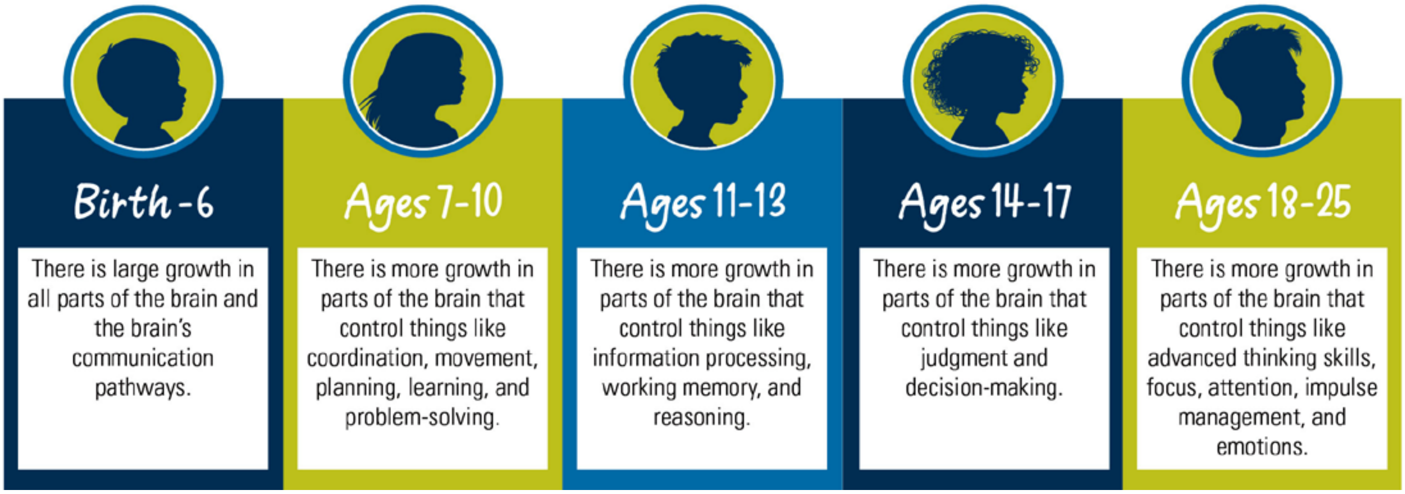
The brain is mostly made up of specialized cells (such as neurons and glial cells), as well as proteins, fats, water, and blood vessels. Each part of the brain plays a role in how the brain works and in allowing different parts of the brain and body to communicate.

A child's developing brain*

A child's brain differs from an adult brain, not only in size, but also in how it works. A child's brain is growing, changing, and developing as a child ages—generally until around age 25. A child's genetics and life experiences affect their brain's development and the formation of communication pathways. Scientists believe that the brain has five "growth periods" during its development. The greatest amount of brain development occurs between birth and age 6.

Takeaways

- A brain injury affects the brain's ability to work and do its normal tasks.
- Symptoms of a brain injury may affect thinking, learning, physical health, communication, emotions, and mood.
- Brain injury symptoms may look different in infants and toddlers than older children and teens.



Birth -6	Ages 7-10	Ages 11-13	Ages 14-17	Ages 18-25
There is large growth in all parts of the brain and the brain's communication pathways.	There is more growth in parts of the brain that control things like coordination, movement, planning, learning, and problem-solving.	There is more growth in parts of the brain that control things like information processing, working memory, and reasoning.	There is more growth in parts of the brain that control things like judgment and decision-making.	There is more growth in parts of the brain that control things like advanced thinking skills, focus, attention, impulse management, and emotions.

*Content in this section is adapted from *BIAA's The Essential Brain Injury Guide 6.0* and a booklet written by Ron Savage, *Brain Development in Children and Adolescents: What Happens After Brain Injury.*

Understanding brain injury*

A brain injury is a physical change in the brain that affects its ability to work and do its normal tasks. Brain injuries resulting from either an external force or an internal cause are called **acquired brain injuries.** In this guide, we will use the term "brain injury" when referring to acquired brain injuries.

External force:

These brain injuries are caused by something outside the body.

- Hitting your head on an object, such as the ground due to a fall
- A hit or force to the head or a blow to the body that causes the head and brain to "whiplash"
- An object entering the skull and brain, such as from a gunshot
- A blast wave from an explosion

Internal cause:

These brain injuries are caused by a problem inside the body.

- A blood clot
- Brain tumor
- Lack of or limited oxygen to the brain (such as from a drug overdose)
- A viral or bacterial infection
- Seizure
- Metabolic disorders (such as those due to diabetes, organ failure, or a lack of important vitamins)
- Poisoning or exposure to a toxin (such as when a person is exposed to high amounts of lead, carbon monoxide, or smoke inhalation from a fire)
- Side effects from a medication or medical procedure

*Content was adapted from: Corrigan JD, Attwood G, Bosworth P, Hammond FM, Juengst SB, Kelly S, Klyce D, Lang K, Marie C, Pappadis MR, Sander AM, Snedaker K, Starr C, Weintraub A, Wolfkiel R. *Communicating About Brain Injury.* J Head Trauma Rehabil. 2025 Oct 6;40(6):E541–3. doi: 10.1097/HTR.0000000000001117.

Common types of brain injuries

Stroke

A stroke is a brain injury that can happen when the brain's blood supply is interrupted or reduced. This can occur due to several factors, such as:

- A burst blood vessel in the brain
- A blood clot that blocks blood flow to part of the brain
- Aneurysms (a bulge in a blood vessel that can leak or rupture)
- Arteriovenous malformations or AVMs (an abnormal connection between arteries and veins which can leak or rupture)

Medical professionals may use the term "cerebrovascular accident" or CVA when referring to a stroke.

TIA (or transient ischemic attacks) are sometimes referred to as "mini-strokes." A TIA is often a warning sign that a stroke may occur.

Traumatic brain injury (TBI)

A TBI results from a physical injury to the brain due to an external force. Some medical professionals may classify TBIs as "mild," "moderate," or "severe" based on specific diagnostic factors. However, experts are working to change this classification system since these terms can be confusing. For example, some children classified as having a "mild" TBI will have symptoms for months or longer that effect their ability to return to school or do other daily activities. See page 21 for more information on TBI diagnosis and classification.

Concussions are a type of TBI. Concussions result from a hit or force to the head or body that causes the brain to bounce, move, or twist in the skull. This movement of the brain is linked to chemical changes, and sometimes damage to or stretching of brain cells. Medical professionals may describe concussions as "mild" brain injuries or "mild TBIs" because they are usually not life-threatening. Even so, the effects of a concussion can be serious.

Brain tumor

A tumor results from the abnormal growth of cells. When a tumor is in or near the brain it is called a brain tumor. There are many different types of brain tumors. Some are cancerous; some are non-cancerous. Depending on the type of brain tumor, it may spread, grow, and/or harm brain tissue. Medical procedures to remove or treat a brain tumor may also lead to a brain injury.

Anoxic brain injury

An anoxic brain injury occurs when there is full loss of oxygen to the brain due to events such as a near-drowning, heart attack, choking, suffocation, drug overdose, and electric shock.

Hypoxic brain injury

A hypoxic brain injury results from a limited supply of oxygen to the brain. This type of brain injury is caused by similar events as an anoxic brain injury.

> *"Brain injury does not define a person. It is just one part of who they are. Judging people based on their limitations can overlook their strengths and abilities."*

Symptoms a child with a brain injury may experience

While the types and causes of brain injury differ, children who sustain a brain injury will experience one or more symptoms. The following table provides some examples of common types of symptoms and what symptoms a child may experience during their recovery journey. It is important to note that each child's symptoms and experience will be unique.

In this guide, we grouped brain injury symptoms into four categories:

Thinking and learning

- Difficulty understanding, thinking clearly, and/or problem-solving
- Trouble learning new skills
- Problems concentrating and/or paying attention
- Difficulty remembering or processing information
- Inability to start tasks (changes in motivation)
- Easily distracted or unable to shift focus

Emotion and mood

- Feeling more emotional than usual
- Nervousness and/or anxiety
- Sadness and/or depression
- Sudden crying or laughing for no clear reason

Physical health and communication

- Headaches
- Weaknesses in arms and legs
- Problems with coordination, balance, hearing, and/or vision (including sensitivity to light or noise)
- Bladder and bowel trouble
- Changes in sensory perception, such as smell and touch
- Difficulty speaking and communicating
- Trouble with sleep (sleeping more or less than usual)

Behavior

- Trouble controlling actions
- Personality changes
- More impulsive than usual
- More angry or aggressive than usual
- Poor judgment and/or increased risk-taking

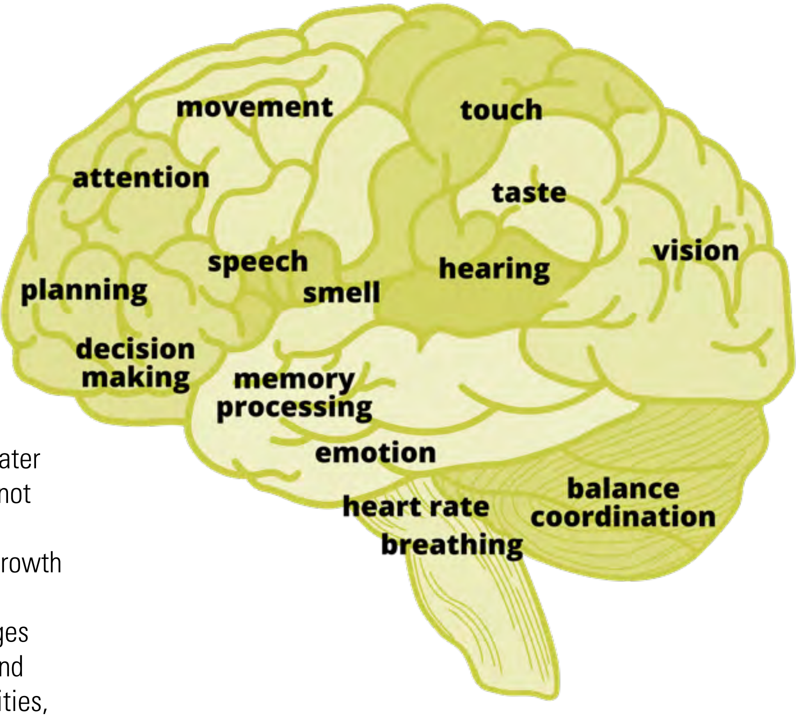
Symptoms in infants and toddlers

Brain injury symptoms appear different in infants and toddlers than they do in older children and teens. For example, after a brain injury, an infant or toddler may:

- Be more irritable or cry more than usual
- Seek more comfort than usual, like needing to be held
- Refuse to nurse or eat
- Avoid playtime or other usual activities
- Need more help than usual or suddenly need help with skills they have already learned (like toilet training)
- Show behavior changes, such as having more temper tantrums
- Have changes in speech, like speaking more slowly than usual
- Seem clumsier or more unsteady on their feet than usual

See pages 40-43 for tips on managing some common brain injury symptoms.

Brain injury *in children*



Some research shows that the developing brain is at greater risk for injury and longer recovery, with some symptoms not becoming noticeable until later in adolescence or during adulthood. For example, a brain injury before a brain's "growth period" might lead to a child to miss skills or effect brain development that happens during that time. These changes may not be obvious at first. However, as the child ages and seeks to do more challenging thinking and learning activities, the effects of this interruption in brain growth may become noticeable. The delay of symptom presentation may result in a brain injury being missed, as symptoms can mirror those of other health conditions, such as Attention-Deficit/Hyperactivity Disorder (ADHD) or a learning disability.

Location of the injury

The symptoms a child experiences may be linked to the location of their injury. Knowing the location of the injury and what function that specific area of the brain is responsible for may help you look for changes or symptoms they may experience. For example, an injury to the back of the brain may affect a child's vision and how they understand what they are seeing. An injury to the front part of the brain may affect a child's ability to plan, pay attention, and/or their ability to think creatively.

Still, it is important to remember that parts of a child's brain are constantly communicating with each other through a network that resembles a bundle of wires. Damage to the brain's communication pathways, as well as chemical changes, also affect the types of symptoms a child may experience.

Brain injuries are chronic medical conditions*

A child's recovery journey after a brain injury may be short (days to weeks) or long (months, years, or lifelong). A brain injury can affect many parts of a child's health and daily life. These effects may stay the same over time, get better, or get worse. Sometimes, symptoms seem to go away but come back later—especially during times of illness, stress, or fatigue. That is why brain injury can be considered a chronic or ongoing medical condition.

> Having a chronic medical condition, like a brain injury, does not mean that your child will not have a good recovery and be able to live a full and productive life.

A healing brain

Research points to the brain's ability to change and develop new pathways that can make up for injured parts of the brain. This is referred to as neuroplasticity—the brain's ability to rewire itself. There are still many unknowns about neuroplasticity. Studies on neuroplasticity are ongoing to better understand how it works and the ways it can support brain health after a brain injury. For example, it is currently unclear why a person with a brain injury may build up considerable hand strength but may be unable to hold a cup. Some research suggests that rehabilitation therapies—such as physical, cognitive, occupational, and speech therapy—can promote neuroplasticity. However, the effects may vary based on the type of brain injury.

*Content was adapted from: Corrigan JD, Attwood G, Bosworth P, Hammond FM, Juengst SB, Kelly S, Klyce D, Lang K, Marie C, Pappadis MR, Sander AM, Snedaker K, Starr C, Weintraub A, Wolfkiel R. *Communicating About Brain Injury.* J Head Trauma Rehabil. 2025 Oct 6;40(6):E541–3. doi: 10.1097/HTR.0000000000001117

Will my child get better?

Every child's experience and brain injury journey will be different. But the good news is that many children living with brain injury will begin to feel better, get back to school, and become active members of their communities. Research is ongoing to determine ways to better predict health outcomes for children after a brain injury. Knowing more about health outcomes can help medical professionals create individualized treatment plans and better identify children in need of specialized care.

Research on brain injury shows that:

Getting medical care right away matters.

The sooner your child gets care for a brain injury, the better the chance for good health outcomes.

Injury severity doesn't always determine health outcomes.

The brain is adaptable and several factors beyond the initial injury affect a child's recovery. That's why two children with similar initial injuries might have very different recoveries.

Post-injury care improves recovery outcomes.

Many of the chronic or long-term health problems that result from a brain injury may be prevented or lessened with appropriate post-injury care.

A strong support system and a positive outlook are good for the brain.

The presence of a strong support system can determine the quality of a child's recovery. Further, a positive outlook and developing good coping strategies often lead to better health outcomes after a brain injury.

A prior brain injury may lead to longer recovery.

A brain injury can have short- or long-term effects. A prior brain injury, even a minor one, may make recovery more challenging.

Chapter 2 Getting medical care for a brain injury

What to expect in the emergency department

For many children, their brain injury journey will begin in an emergency department. This is especially true if your child arrives in an ambulance, is unconscious or unable to stay awake, or is experiencing severe symptoms like increasing confusion, repeated vomiting, seizures, or difficulty standing.

The experience in the emergency department can feel stressful. Medical professionals may ask you to make quick decisions or respond to a lot of questions about your child. The role of medical professionals in the emergency department is to determine who is at risk for life-threatening injuries, who should be admitted to the hospital, and who can go home. They will also take steps to diagnose, treat, and prevent a medical condition from getting worse.

What to expect in the hospital

After receiving emergency medical care, the medical team will decide whether your child can recover at home or if they need to be admitted to the hospital for specialized care. Most children with a concussion can recover safely at home. However, children with other types of brain injury may be sent for care in the hospital. This may include being in the pediatric intensive care unit (PICU) for care and monitoring by the medical team. Medical teams in a PICU will be on hand 24 hours a day, seven days a week.

If your child is admitted to the PICU, you will be able to visit them as soon as the medical team determines it is safe to do so. The medical team may also limit the number of visitors your child can have while in the PICU.

CARE Act

Many states have a law in place, called the CARE (Caregiver Advise, Record, Enable) Act. This law requires hospitals to:

1) Record the names of family caregivers in their loved ones' medical records.
2) Inform family caregivers about when their loved one will be sent home from the hospital.
3) Provide family caregivers with education and instructions on medical and care tasks that will need to be done at home.

To see if your state has passed the CARE Act, visit **https://ltsschoices.aarp.org/scorecard-report/2023/dimensions-and-indicators/care-act-legislation**

Takeaways

- Medical professionals may do several tests and use equipment to learn about your child's brain injury and its effects on their brain.
- Medical professionals have treatment plans that can help address many of the health problems that appear after a brain injury.
- It is important to get involved with treatment and discharge planning to make sure your child's and your family's needs are met.

> *"Be an advocate for your loved one and their needs."*

Managing secondary injuries

Your child's medical team will watch for secondary injuries after a brain injury. Secondary injuries are health problems that are linked to physical changes in your child's brain, such as swelling, bleeding, or changes in blood flow and oxygen that can cause more harm to their brain. Medical professionals will create treatment plans to help address or lessen the effects of secondary injuries on your child's brain.

Brain swelling

Brain swelling occurs when too much fluid builds up in the brain (and inside the skull). This can lead to pressure on the brain that can harm brain cells or affect blood flow in the brain.

Hematoma

A hit to the head can cause blood vessels to break, forming a hematoma or a pool of blood, inside the brain. This may lead to damage to brain cells or brain swelling.

Hydrocephalus

Hydrocephalus occurs when the flow of fluid into different parts of the brain is blocked or disrupted. Fluid can build up and lead to pressure in the brain.

Hypovolemic shock

A child with a brain injury may lose a lot of blood. A big loss of blood may affect the heart's ability to pump enough blood to meet the body's needs, leading to hypovolemic shock.

Intracranial pressure

Pressure in the brain due to fluid buildup or bleeding is called intracranial pressure or ICP. ICP can harm brain cells.

Tips for families:

- ✓ Wear a hospital gown, gloves, or a mask (if requested by the medical team) to lower the chance of spreading infection to your child and other patients.
- ✓ Talk to your child in your regular voice, even if they are unconscious or sedated.
- ✓ Share positive thoughts and stories with your child.
- ✓ If the medical team determines it is safe to do so, hold your child's hand.
- ✓ Ask your child's medical team about visiting hours and share this information with friends and family.

Practice self-care

Time spent in the hospital can feel stressful and overwhelming. While your focus will be on your child as they recover, it is important that you take care of yourself. This includes:

- Getting enough sleep.
- Eating well and staying hydrated.
- Exercising (even if that means just taking short walks outside the hospital).
- Asking for and accepting help from others.

Most people mean it when they say, "Let me know if there is anything I can do to help." They just may not know what you need. You may find it helpful to make a list of things that people can help with and to identify someone who can help you assign tasks to friends and family. Check out some additional tips for caregivers on pages 57-59.

Checklist:
When your child is in the hospital

☐ Use a notebook or a notes app to record daily events and to write down questions for the medical team.

☐ Collect medical records, test results, and other information to help manage insurance and determine eligibility for Medicaid or other programs. Keeping a list of your costs to help you track medical expenses may also help.

☐ Activate your support network.

- Ask someone to be a point of contact to help you communicate with family and friends.
- Reach out to others for help with tasks, such as preparing meals (for home and while you are visiting your child in the hospital), feeding and walking pets, caring for other children, doing laundry, shopping for groceries, watering plants, and cleaning the house.

☐ Talk to others about your feelings. Hospitals have chaplains and social workers who are available to speak with you and provide support and understanding.

☐ Track your child's medications (names, doses, times, and side effects). You can find a template for medication tracking on page 67.

☐ Bring familiar items, such as a blanket, stuffed animal, or photos for yourself and your child to provide comfort.

☐ Talk, sing, or read to your child (if allowed by medical team).

☐ Ask your child's medical team about safe positioning, movement, or stimulation.

☐ Monitor changes in your child's mood, behavior, or alertness and share this information with the medical team.

☐ Ask for clear explanations of medical terms and treatments, especially if there is something you don't understand or that seems unclear to you.

> *“I acknowledged that caregiving was stressful and that it was normal to feel angry at times. I wasn't a saint and didn't have to act like everything was under control. I reached out to others for help when I felt overwhelmed. I took breaks and carved out time for myself. Caregiving filled me with exasperation and hopelessness at times, but it was my ultimate expression of love.”*

Tips for families:

- ✓ Fill out and hang a handout with information about your child in the hospital room (see example on page 17).
- ✓ Share positive, calming words and stories, and speak gently to your child.
- ✓ Place photos and comfort items where your child can see or feel them (if approved by the medical team).
- ✓ Use their name and talk with your child as if they can understand.
- ✓ Limit noise, stress, and too many visitors at once.
- ✓ Read aloud from your child's favorite book or play soft music (if approved by the medical team).

Remember:

Your child may not be able to respond, but they may still hear and feel what is happening around them.

Understanding Disorders of Consciousness

There are three types of disorders of consciousness:

1. Coma

A coma is a state of complete unconsciousness. A child in a coma appears to be in a deep sleep with their eyes closed. The child cannot be woken up and does not respond purposefully to noise, pain, or other stimulation. Medical tests also show that the child has no sleep/wake cycles.

2. Unresponsive wakefulness syndrome (UWS)*

UWS, previously referred to as vegetative state, includes wakefulness without awareness. This means that the child may open and close their eyes, make sounds (especially when moved or stretched), may cry or smile, move their eyes toward people or things, and react to sound. However, they are unable to follow instructions, communicate, or make purposeful movements.

3. Minimally conscious state

A child in a minimally conscious state may follow simple instructions from time to time and be able to indicate "yes" or "no" by talking or gesturing. They may also say some words or phrases and move their head, arms, and legs. They are unable to consistently respond to instructions and may take time to respond to questions.

Locked-In Syndrome

Children experiencing locked-in syndrome are conscious

Locked-in syndrome means that a child is conscious, but they are unable to move or communicate due to problems with muscles in the face, arms, and legs. Some children are able to communicate using eye movements and blinking.

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*After a brain injury, some people may look unresponsive or unconscious at the bedside due to an inability to communicate or move when asked. However, special brain scans and electrical tests can sometimes show that the person has some level of awareness. This condition has been referred to as "covert consciousness," among other diagnostic labels. These situations can be very complex medically, ethically, and legally, and without the right testing, a person may be incorrectly diagnosed as having a UWS.

Thank you for caring for me.

The name I like to go by is: ____________________

Here is some information to help you get to know me.

My loved ones ask that you please:

- Talk to me as if I can hear you
- Explain what you are doing before touching or moving me

I am ________ years old.

I am in grade ____________.

I have _________ siblings and ____________ pets.

My favorite things to do include: ____________________

____

I may become stressed, scared, or upset when: ____________________

____

These things give me comfort: ____________________

____

I feel calm and relaxed when: ____________________

____

My favorite music is: ____________________

____

My favorite people in the world include: ____________________

____

These cultural or religious practices are important to me: ____________________

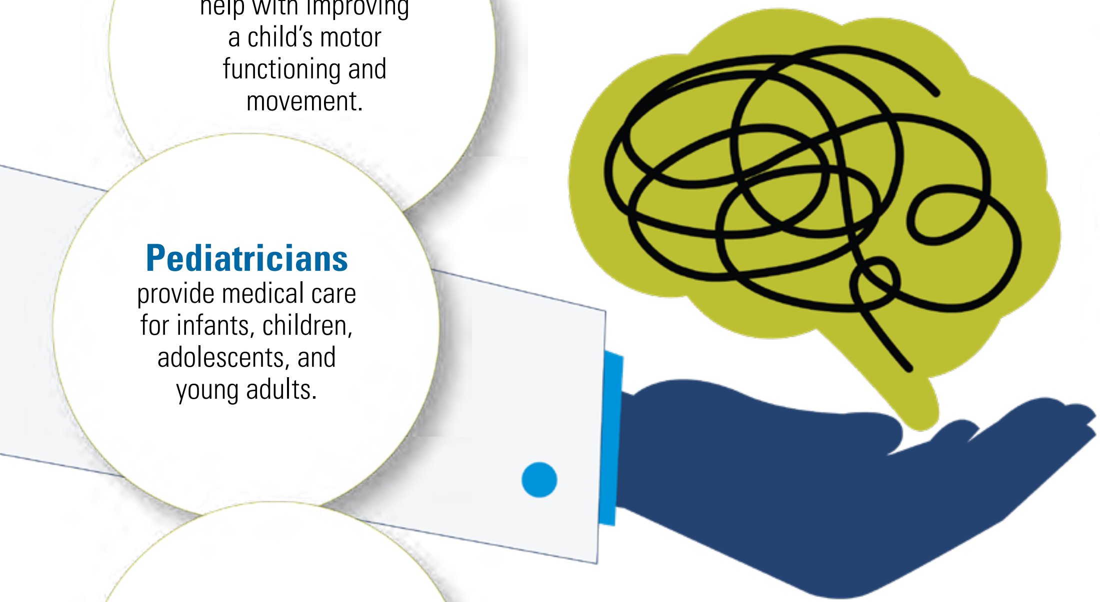
____

[If your child's medical team allows it, fill out this handout and hang it in your child's hospital room.]

Brain Injury Association of America

Your child's medical team

Many professionals and specialists are involved in the care of your child in the hospital. Examples of some members of the medical team are included on this page. For more information on who might make up your child's medical team, visit www.biausa.org/clinicians.



Rehabilitation nurses monitor all the body systems to maintain a child's medical status and watch for complications.

Physiatrists lead the rehabilitation team and coordinate its goals into a unified approach.

Neurologists diagnose and manage care for children with health conditions that affect the nervous system, including the brain and spinal cord.

Neuropsychologists test changes in a child's brain, including changes in thinking, mood, and learning.

Occupational therapists help children improve physical and cognitive skills required to do their regular daily activities.

Speech-language pathologists help children improve communication and swallowing.

Case managers help coordinate appropriate and cost-effective treatment options and preparing for discharge from the hospital.

Trauma surgeons perform non-brain surgeries and other therapies aimed at limiting health problems after a brain injury.

Neuropsychiatrists diagnose, as well as prescribe and monitor medications for health conditions that affect behaviors and changes in personality, mood, memory, and sleep.

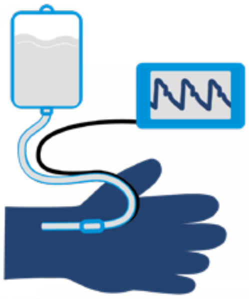
Neurosurgeons perform surgery on the brain and have expertise in diseases of the central nervous system.

Pediatricians provide medical care for infants, children, adolescents, and young adults.

Physical therapists help with improving a child's motor functioning and movement.

Medical equipment

The sights and sounds of a hospital can feel a bit scary. You might see tubes and lines attached to your child or hear alerts coming from the machines monitoring their vital signs. While these technologies help the medical team keep track of your child's progress, they can look strange at first. To help you get familiar with some of the hospital equipment you might see, below are some examples of commonly used medical equipment.



Arterial line

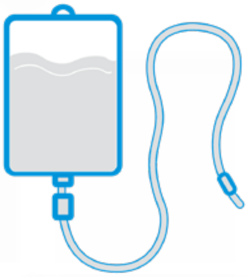
A tube placed in the blood vessels to measure blood pressure.

Electroencephalogram (EEG)

A machine placed on the head that measures the brain's electrical activity. An EEG can check for seizures or decreased brain activity.

Electrocardiogram (EKG)

A machine with small electrodes that are placed on the chest, arms, and legs that assesses the function and electrical activity of the heart.



Intravenous (IV) line

A tube placed in a person's veins to deliver medications or fluids to their body.

Nasogastric (NG) tube

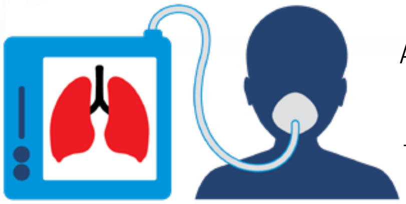
A tube inserted through the nose that delivers medication and nutrients to a person's stomach.

Intracranial pressure (ICP) monitor

A monitor that measures pressure in the brain by placing a device inside the head.

Pulse oximeter

A device placed on a person's finger, toe, or ear lobe to measure their oxygen levels.



Ventilator

A machine that moves air in and out of a person's lungs using a tube that is placed through the person's mouth and windpipe.

Common medical tests

Medical professionals may use several tests to learn about your child's brain injury and its effects on their brain. The types of tests used may vary depending on the cause of the brain injury and whether the child is unconscious. Some examples of medical tests are provided on the following pages.

Imaging tests

Angiogram

An angiogram uses X-rays and contrast dye to help medical professionals see a child's blood vessels and detect problems like blockages, aneurysms, or problems with blood flow.

Skull X-ray

Skull X-rays can show damage to the skull (such as a skull fracture) and other bones and help medical professionals determine if there are pieces of bone or foreign objects in the brain.

Magnetic Resonance Imaging (MRI) and Computerized Tomography (CT)

MRIs and CTs play important roles in identifying bleeding and swelling in the brain. MRIs and CT scans are not commonly used for routine diagnosis of concussion as the chemical changes in the brain are not visible using these tools.

Neurological and other tests

Glasgow Coma Scale (GCS)

GCS measures a child's ability to respond to simple commands, including their ability to move, open their eyes, and answer questions. GCS scores range from a low of 3 to a high of 15. When a GCS test is administered by a medical professional, a child may experience arm and leg spasms, but this is not harmful. A child's initial GCS score may not be linked to their overall health outcomes after a brain injury.

Electroencephalogram (EEG)

EEG measures the brain's electrical activity. It may be used to help evaluate the severity of a brain injury and monitor recovery, as well as to assess neurological conditions like seizures and patients who experience a change or loss of consciousness.

Intracranial pressure (ICP) monitor

An ICP monitor is used to measure the pressure in the brain to determine whether swelling is going down on its own or if other treatments are needed.

Pediatric National Institutes of Health Stroke Scale (PedNIHSS)

The PedNIHSS measures consciousness, vision, sensation, movement, speech, and language.

Tests for post-traumatic amnesia (PTA)

Tests for PTA are used to determine a child's ability to recall events before and after a brain injury. Examples may include the Children's Orientation and Amnesia Test (COAT) and the Orientation Log (O-Log).

Coma Recovery Scale (CRS)

The CRS is used to assess the level of consciousness among children with disorders of consciousness.
It examines sight, hearing, body movement, mouth movement, communication, and wakefulness.

Diagnosing TBI

To improve diagnosis and treatment of TBI, experts reviewed decades of research to create a new way to characterize this injury. The proposed framework moves away from the terms, "mild," "moderate," and "severe," as they primarily focus on a person's initial symptom presentation. Instead, characterization is based on four criteria for use by medical professionals.

Experts are working to increase awareness and support use of this new system for diagnosing TBI. It will take time for widespread use of this system in medical settings across the country.

Clinical signs and symptoms

Medical professionals use the GCS score to determine a person's level of consciousness as well as how a person's pupils react to light. Clinical criteria also include assessing:

- Responses to eye, verbal, and motor commands or stimuli.
- Presence of amnesia.
- Symptoms of TBI, like headache, dizziness, and noise sensitivity.

> *"As a caregiver, breaks are so important. I found it incredibly helpful. Taking time for myself (even if it was just 30 minutes outside alone) was a nice 'reset' for myself. At first it feels selfish but building that in as part of our routine was so beneficial for all of us."*

Blood-based biomarkers

Medical professionals use blood tests to help identify people at risk for bleeding on the brain or tissue damage after a TBI, and if they should undergo imaging, such as CT or MRI.

Imaging

Medical professionals use imaging, like CT and MRI, to identify blood clots, bleeding, lesions, and skull fractures that may need emergency care.

Modifiers

Medical professionals review factors that influence the patient's clinical presentation and long-term outcome, such as a person's age, how the injury occurred, pre-existing health conditions, medications used, and lifestyle factors (such as mental health problems and substance use disorders).

Examples of some possible health problems after a brain injury

Some health problems after a brain injury show up right away and need emergency care, while others may not show up for days, weeks, or even months following the injury. **Medical professionals can create treatment plans to help address many of these health problems.**

Aphasia

Aphasia affects a person's ability to speak or understand speech, read, or write. There are different types of aphasia:

- **Expressive aphasia:** A person has difficulty speaking but understands speech.
- **Receptive aphasia:** A person can speak but may use incorrect words or have trouble understanding and processing information.
- **Global aphasia:** A person has difficulty with speaking and understanding speech and may not be able to read or write.

Bladder and bowel incontinence

Bladder and bowel incontinence involves the loss of bladder and bowel control due to problems with communication pathways between the brain and a child's bowel and bladder muscles. This can lead to bed wetting and a child having problems getting to the bathroom in time.

Blood clotting disorders

Blood clotting disorders may lead to an increase in bleeding and blood clots in the brain.

Dysarthria

Dysarthria is a speech disorder caused by weakened muscles that affect speech clarity. For example, a child may speak slowly or slur their words.

Gastrointestinal/nutritional problems

Gastrointestinal/nutritional problems may include bleeding, reflux, constipation, or other bowel problems. A child may require a feeding tube to support their nutritional and energy needs.

Hemiparesis and Hemiplegia

Hemiparesis means weakness on one side of the body, while hemiplegia means paralysis (no movement) on one side of the body.

Mental health problems

Children living with brain injury are at increased risk for common mental health problems, including depression, anxiety, and post-traumatic stress disorder (PTSD). New or increasing mental health problems can occur right away or years after a brain injury.

Motor dysfunction

Motor dysfunction might include tight or spastic muscles, poor coordination, tremors, weakness, and trouble with balance.

Paroxysmal Sympathetic Hyperactivity (PSH)

Sometimes referred to as "storming," PSH happens when the part of the brain that controls autonomic body functions—like heart rate, breathing, temperature, and blood pressure—is injured and is not working correctly. PSH is linked to increased sweating, heart and breathing rate, as well as higher body temperature, blood pressure, and muscle activity. Some children experiencing PSH will feel faint or nauseous when they stand up. Others may have headaches or feel overly tired.

Post-traumatic headaches

Post-traumatic headaches are linked to pain or throbbing in the head. A person may also experience nausea or vomiting, sensitivity to light or sound, and blurred vision. Headaches are the most common symptom experienced by children after a brain injury.

Problems with hormone production

Damage to parts of the brain that control hormone production may affect a child's growth, energy, mood, sleep, puberty, and hunger.

Pseudobulbar affect (PBA)

PBA is a condition that leads to involuntary, sudden, and frequent laughing or crying that does not match how the person feels or the situation.

Respiratory problems

Respiratory problems may include slow or irregular breathing, sleep-related breathing problems, breathing too fast or shallow, and/or needing help to breathe with medical equipment.

Seizure disorders

A seizure involves the sudden appearance of convulsions (or shaking), problems with sensation, or a loss of consciousness.

Sensory issues

Some children have trouble with how they sense and feel the world around them due to problems with processing information.

Sexual disinhibition

Sexual disinhibition may include inappropriate sexual behaviors, including unwanted hugs, kisses, and flirtatious advances.

Spasticity

Spasticity involves muscle tightness or stiffness in the arms and legs.

Substance use disorders

Children living with brain injury are at increased risk for substance use disorders. Use of alcohol and illegal drugs after a brain injury can affect recovery. There is no safe amount of alcohol or illegal drugs for a person recovering from a brain injury.

Unexpected bone growth

After a brain injury, some children develop extra bone in places where bone shouldn't grow, such as in the muscles, joints, or soft tissues.

Vision problems

There are several types of vision problems a child may experience. Examples include:

- **Visual neglect:** The brain of a child with visual neglect ignores half of their body, even though their eyes are working normally.
- **Convergence insufficiency:** A child's eyes have trouble working together to focus on something close, like a book.
- **Cortical visual impairment:** A child can see things, but their brain has difficulty understanding what they see.

Tips for families:

- ✓ Keep track of medications given to your child. You can use the chart on page 67.
- ✓ To learn about programs that offer free or discounted medications, see page 66.

Medical Interventions

Many health problems that result from a brain injury may be prevented or lessened with medications and medical interventions or treatments. Each child with a brain injury receives an individualized treatment plan based on their medical needs. Examples of some interventions and treatments for brain injury may include:

Fluid restriction

A child might not be allowed to drink fluids during treatment for a brain injury. This is because the fluid a child drinks may be absorbed by the brain, causing it to swell.

Positioning

The head of the bed may be slightly raised to prevent a buildup of fluid and pressure in the brain.

Neurosurgery

Any of the following procedures may be performed:

- **Burr holes or burring:** The surgeon makes a small opening in the skull to remove blood clots.
- **Craniotomy:** The skull is opened to relieve pressure caused by a broken bone, blood clots, or swelling. The piece of the skull is removed and later replaced.
- **Ventricular drainage:** The surgeon inserts a catheter leading from the brain into the abdomen to drain spinal and brain fluid.

Medications

Medical professionals may prescribe:

- Antibiotics to prevent infections.
- Antiseizure medication to control seizures.
- Anti-spasticity medications to decrease muscle tone and prevent seizures.
- Antidepressants to reduce feelings of depression.
- Antianxiety medication to lower anxiety.
- Psychostimulants to increase alertness.

How will we afford my child's care?

Unfortunately, expensive medical treatment combined with time spent away from work can place significant financial stress on a family. The following are some options to explore. You can also **call the National Brain Injury Information Center at 1-800-444-6443** to learn about financial support and assistance in your community. See page 66 for information on programs that offer free or discounted medications. If your child was injured at work, see page 68 for information on Workers' Compensation.

Supplemental Security Income (SSI) benefits

You may be eligible for Supplemental Security Income (SSI) benefits on behalf of your child. These benefits provide families with help covering everything from medical expenses to the costs related to daily living, such as groceries. Learn more about applying for SSI benefits on pages 63-64.

Medicaid

Medicaid is a joint federal and state program that offers medical coverage for people who meet specific income requirements and/or who are living with disabilities. You can read more about Medicaid on page 65. Many states pay family caregivers through self-directed programs, such as Home and Community-Based Services waivers. Further, some Medicaid programs offer **Brain Injury or Traumatic Brain Injury Waivers**. These waivers include services like rehabilitation, case management, and supported employment. Be sure to check if there are age requirements for the waiver program in your state.

Children's Health Insurance Program (CHIP)

In some states, CHIP provides low-cost health coverage to children and pregnant women in families that earn too much money to qualify for Medicaid but need help with covering medical and other costs. Visit **www.healthcare.gov** to learn more.

State 211

Many states have community specialists who are available to help you access local resources and services, including help with housing, transportation to medical care, paying for utilities, and programs for people living with disabilities. Call 2-1-1 or visit www.211.org to learn more.

State Cash Financial Aid

Some states and local governments offer cash assistance programs to people living with disabilities and to military veterans. Find your state **Brain Injury Association at www.biausa.org/find-bia** for more information.

Other federal programs

You can visit **usa.gov/benefits** to get information on federal government programs that may help you pay for food, housing, healthcare, and other basic living expenses. **Some government programs pay family or friends of people with disabilities to help with daily activities (www.usa.gov/disability-caregiver).** This can include personal care, giving medicine, cooking, and cleaning. In addition, there are free- and low-cost health centers across the country that provide medical services regardless of a person's ability to pay. Visit **findahealthcenter.hrsa.gov.**

Private insurance

Federal law currently prevents insurance companies from denying new coverage to people due to health status, medical history, prior insurance claims, genetic information, and disability. Visit **www.healthcare.gov** to learn more. You can read more about private insurance coverage on page 71.

Be prepared to fight denials and to negotiate with your insurance company. Call the **National Brain Injury Information Center at 1-800-444-6443** to get information on insurance and Medicaid issues. BIAA has also published a free guide called "Navigating the Insurance Maze" that can be downloaded at www.biausa.org/insurance.

Preparing to leave the hospital (discharge planning)

Discharge planning usually begins within the first few days of your child's arrival at the hospital. Social workers and/or case managers will help you and your child's medical team identify options and determine your child's next step in treatment and care. Unfortunately, health insurance and the ability to cover the costs of your child's care outside the hospital play a large role in discharge planning.

Types of questions to ask medical professionals before discharge

Moving from a hospital to a rehabilitation facility or back home can be emotional, exciting, overwhelming, and exhausting. Here are some questions to ask your child's medical team as you prepare for your child's discharge from the hospital.

Discharge timing

☐ Who decides when my child is ready for discharge from the hospital and how is it decided?

☐ What can I do if I disagree with the decision to discharge my child from the hospital?

☐ What factors can affect when my child is discharged from the hospital?

☐ How much time in advance will we know that my child is being discharged?

Care after the hospital stay

☐ What are the different care options available to my child upon leaving the hospital?

☐ What happens if the care option that is best for my child is not currently available?

☐ What can we do if we are unable to make our home ready to meet the care needs of our child?

☐ Where should my child get follow-up care? What type of specialists should they see?

☐ Where can I get a list of resources for support in my community, like my local brain injury association, case management, and home-based care?

☐ How can I help my child return to school? (See pages 47-49 to learn more about helping your child return to school.)

☐ Is there information or training to help me learn how to:
  - Use the feeding tube?
  - Manage medications?
  - Assist with any physical or cognitive therapies?
  - Set up my home?

☐ What things do I need to watch for that require emergency care or should be reported to the medical team?

Keeping records

☐ How do I get a complete set of my child's medical records?

☐ Is there a charge for getting medical records?

Chapter 3

Rehabilitation Services

Goals of rehabilitation services

Your child may need rehabilitation services after a brain injury. The goals of rehabilitation services are to improve the overall quality of life for children and adults living with brain injury and prevent or lessen the health problems that may result from this injury. This may include helping them:

- Re-learn skills or learn how to do skills differently.
- Do daily tasks independently.
- Engage with friends and family.
- Return to school.
- Work, volunteer, or participate in community activities.

Through rehabilitation services your child may learn how to do skills a different way than before the injury. For example, after a brain injury a child may walk with help from a cane or walker. They may also need checklists or alerts to help them remember things. Home modifications or specialized equipment (like ramps, transfer boards, and splints) may also be necessary to help them do their daily activities.

Types of rehabilitation services

Rehabilitation services may be provided in medical, home, or community-based settings. Examples of rehabilitation services are covered on the following pages.

Comprehensive Integrated Inpatient Rehabilitation Facility (IRF)

IRF services are provided in a special unit in the hospital or in a facility that only does inpatient rehabilitation. Some IRF services focus especially on people who have experienced a brain injury. At an IRF:

- Your child will receive medical and nursing care, as well as physical, occupational, recreational, and speech therapy for several hours a day based on their health needs.
- Medical teams will be on hand 24 hours a day, seven days a week.
- The length of stay will depend on:
  - The medical needs of your child.
  - Whether medical complications arise.
  - Your child's progress.
  - The limits of your insurance or other medical coverage.

Takeaways

- Rehabilitation services are available for all types of medical and care needs.
- It is important to do research and ask your child's medical and rehabilitation teams questions before choosing a rehabilitation program.
- Get involved with treatment and discharge planning to make sure your child's and your family's needs are met.
- There are programs available for families who are unable to provide care for their child at home.

Do research and ask your child's medical team about the best options for them. You can call the **National Brain Injury Information Center at 1-800-444-6443** to learn about where to get help with care needs and other brain injury services in your area.

Long-term acute care hospital

Long-term acute care hospitals offer rehabilitation services for children and adults with brain injuries who have multiple or complex medical problems. Medical management and therapeutic care are provided 24 hours a day, seven days a week. A long-term acute care hospital is often the next step after being discharged from the PICU if your child:

- Is on a ventilator.
- Needs other life-support assistance.
- Has serious medical conditions that require intense, specialized treatment.

Subacute skilled nursing facility rehabilitation program

A subacute rehabilitation program may be recommended if your child:

- Cannot tolerate therapy for a minimum of three hours per day, five days per week.
- Is progressing but not making rapid functional gains.

Subacute rehabilitation programs are in separate and specially licensed units of hospitals or freestanding skilled nursing facilities.

Transitional rehabilitation/Residential rehabilitation facility

Transitional rehabilitation (TR) is comprehensive, residential treatment that includes intensive physical, cognitive, and behavioral therapies. TR facilities also offer counseling, education, and medical care as needed. TR facilities focus on re-learning skills and functions, along with use of supports, such as assistive technologies, and environmental modifications to improve function, with the goal of preparing people to return home. TR is appropriate for children who:

- Have completed acute hospital-based rehabilitation.
- Are medically stable.
- Are able to participate in intensive therapy (such as physical, occupational, recreational, and speech therapy).

TR is also suitable for people who may not have received hospital-based rehabilitation, are unable to be sent home, or who are at risk of developing medical complications or re-injury. Some facilities will care for people experiencing a disorder of consciousness.

Neurobehavioral and behavioral residential rehabilitation

Neurobehavioral and behavioral residential rehabilitation programs specialize in treatment of individuals with a brain injury who are:

- Experiencing depression and thoughts of suicide.
- Showing aggressive, violent, or sexually inappropriate behaviors.
- Managing substance use or psychiatric disorders.
- Living with other health conditions that may complicate their care and recovery journey.

These programs:

- Are usually provided in a locked unit of a hospital or rehabilitation facility.
- Use behavioral strategies, medications, and social and cognitive therapies.
- Offer treatment for substance use disorders.
- Provide family counseling to help support care.

Psychiatric hospitals that do not have programs designed to care for people with brain injury are not a substitute for these programs.

Be wary of "quick fix" promises

Throughout your child's brain injury journey, it is likely they will struggle. You may find yourself feeling overwhelmed and willing to try anything you can to help your child recover. That is completely normal. However, it is important to be cautious. The internet—social media, podcasts, forums, and more—is full of individuals and companies marketing products, supplements, treatments, and services that claim to more quickly heal or cure the brain or relieve symptoms. Be especially wary of anything that promises to be a "quick fix." Not everything you hear will be honest, safe, or backed by science.

Be sure to:

- ✓ Only give medications or supplements to your child that are approved by their medical team.
- ✓ Talk to your child's medical team about treatment options.
- ✓ Steer clear from untested and unapproved treatments.
- ✓ Look for information from credible sources, including leading medical and health organizations.

Finding the Right Rehabilitation Program for Your Child*

Ask a lot of questions

Ask questions about staff levels and training, service philosophy, and how they report updates and outcomes for their patients. Discuss whether families can attend therapy sessions, where families can stay if the facility is far from home, and the expected length of stay for your child. Bottom line, learn as much as you can and **visit the facility in person and meet with the staff**, when possible.

Learn from others

Talk with others about their experiences with rehabilitation services. Support groups are often a good way to find people who have knowledge about different programs and services in your community.

Ask if staff have ACBIS certification

ACBIS, or the Academy of Certified Brain Injury Specialists, is the nation's largest and longest running professional brain injury certification program. Learn more at www.biausa.org/acbis.

Explore multiple program options

The closest program or the one that offers the most services may not necessarily be the best fit for your child. Be wary of anyone who tries to pressure you. Remember that the quality of services cannot be judged solely by how nice the facilities or marketing materials appear.

Get information in writing

Keep notes on who you spoke to, the date, and a summary of your conversation. Get any agreements in writing, including the types, quantities, and costs of services that will be provided to your child before you finalize your decision.

Understand your medical coverage

Review a copy of your insurance policy or health plan. Depending on what kind of services are needed, talk with your insurance carrier, managed care organization, or other health care payer to find out what costs they cover and about deductibles and co-payments. Request regular updates from your insurance provider about costs and coverage.

Be involved, stay involved

Voice your opinions, questions, and concerns right away. Choosing brain injury programs and services is one of the most important decisions of your child's brain injury journey. Once services begin, stay on top of what is being provided and what other options exist.

The Commission on Accreditation of Rehabilitation Facilities (CARF) International has developed standards and recognizes medical rehabilitation programs that meet the highest level of quality of care. You can ask a rehabilitation program if they are accredited by CARF. You can also visit the CARF website at https://carf.org/find-provider to find facilities in your area.

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*Content is this section is adapted from an article that originally appeared in the *Brain Injury Association of America- Maine Chapter Brain Injury & Stroke Resource Directory*, Second Edition.

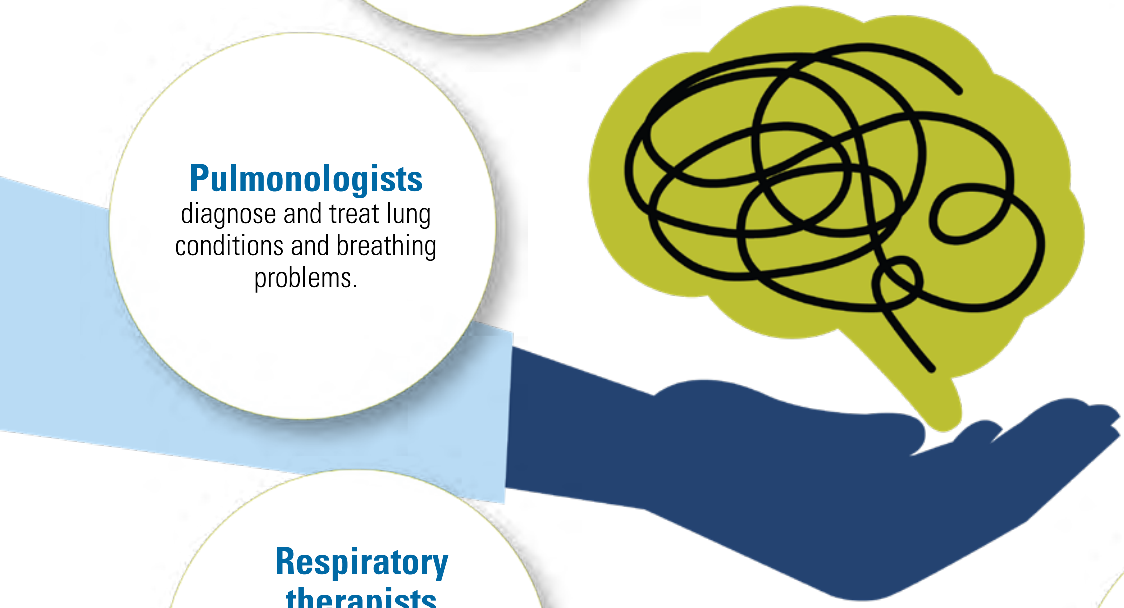
Your child's rehabilitation team

Members of your child's rehabilitation team may include many of the members of their medical team, such as physical therapists, occupational therapists, and speech-language pathologists (see page 18). However, there are new types of medical and health professionals you may encounter on their rehabilitation team. The rehabilitation team is generally led by a physiatrist. Sometimes the rehabilitation team will reach out to other experts, such as orthopedic surgeons, radiologists, urologists, endocrinologists, otolaryngologists, and audiologists, for insights on care. Members of the rehabilitation team generally have completed specialized training and certifications in brain injury. One example certification program is the **BIAA Academy of Certified Brain Injury Specialists program (www.biausa.org/acbis)**.

Aquatic therapists provide therapy in heated pools to assist people with coordination, movement, endurance, and pain management.

Neuro-ophthalmologists diagnose and treat vision problems resulting from a brain injury.

Neuro-optometrists diagnose and prescribe glasses or other technologies to help improve a person's vision after a brain injury.



Pulmonologists diagnose and treat lung conditions and breathing problems.

Registered dietitians help improve health through food and nutrition.

Respiratory therapists provide care for health conditions affecting breathing and instruction on the use of breath-related equipment and technology.

Recreational therapists plan activities to help people practice skills in real-life settings, such as sports, gardening, and social events.

Vocational rehabilitation counselors assess a person's work and educational experience with the goal of helping them find a job.

Treatment planning

Different members of your child's rehabilitation team will likely do evaluations to better understand your child's abilities and medical needs. One such exam is a neuropsychological assessment. This type of assessment helps the rehabilitation team identify your child's strengths and weaknesses related to thinking, reaction time, memory, ability to pay attention and understand information, communication, problem-solving, mood, and behavior. Other types of tests will focus on your child's physical abilities, like balance, walking, and coordination. The team will then work together to create a treatment plan that is based on your child's abilities and medical needs.

The treatment plan should include:

- Overall treatment goals.
- Recommended therapies.
- How often they receive therapies.
- List of any medications (if needed).
- Expected length of stay in the program.
- Support and resources for caregivers.

Treatment meetings

Treatment meetings are your opportunity to get reports and updates from the rehabilitation team about how your child is progressing. During these meetings be sure to:

- Ask questions and request explanations for things that are unclear.
- Get involved in goal setting for your child's treatment.
- Ask about programs to support families and caregivers, including counseling and mental health services.
- Learn about community- and home-based services for your child.

Preparing to leave a rehabilitation program (discharge planning)

Social workers and/or case managers will help you and your child's rehabilitation team identify options and determine your child's next step in treatment and care. As with discharge from a hospital, health insurance and the ability to cover the costs of your child's rehabilitation care play a large role in discharge planning. Be sure to communicate with the team right away if you believe that you and your family will be unable to meet the care needs of your child at home.

> *“Keep advocating for your loved one. If you think something isn't working, speak up, get second and third opinions, and ask questions. Speak to other caregivers to get support and guidance and never give up.”*

If you believe that your child is not ready for discharge and should stay in a rehabilitation program, speak with your insurance provider or other coverage provider, as well as your child's social worker or case manager. In some situations, insurance companies will approve extended lengths of stay in a rehabilitation program if a person continues to make improvements. You may need to involve a lawyer to help advocate for your child. **Call the National Brain Injury Information Center at 1-800-444-6443** to get information on insurance, Medicaid issues, and where to find financial and legal resources.

Things to consider before your child is discharged

Set up a care plan

Depending on the needs of your child, you may need to:

- Assist with or identify someone who can provide day or nighttime supervision and care, including help with bathing and toileting.
- Learn how best to physically lift, transfer, or move your child.
- Get familiar with medical equipment and supplies.

Ask about training and support

Request training opportunities on how to care for your child, such as how to:

- Care for skin ulcers or contractures (changes to soft or connective tissue that can cause it to stiffen, tighten, and contract).
- Manage swallowing or bowel and bladder issues.
- Assist with feeding and feeding tubes.
- Help with symptom management (see pages 40-43 for tips on managing common symptoms).
- Organize and give medications (see page 67 for a medication tracker and page 66 for information on programs that provide free or discounted medications).

Make safety changes to your home

Ask for a home evaluation by an occupational therapist. Creating changes in your home may help make the transition easier and safer for your child. This may include:

- Modifying the living space to minimize fall risks, such as installing grab bars in showers, improving lighting, and removing throw rugs.
- Posting signs and instructions to help with thinking and memory.
- Creating a separate space (when possible) for your child or other family members to go to be alone or have quiet time.
- Using appliances with automatic shut-off features.
- Installing items to help with mobility, such as ramps, door openers, roll-in showers, and wider doorways.
- Setting up door alarms if your child may wander outside, especially if they have access to a pool.
- Using unbreakable or shatterproof dishes and cups.

Learn about transportation options

- Plan for accessible transportation, especially if your child needs a mobility aid.
- Ask others to help with transportation needs or explore rideshare options.
- Learn about returning to driving after brain injury (you can find more information on page 53).
- Explore accessible options available through public transit.

Prepare family and friends

- Everyone responds differently to change and the need to manage the care of a loved one. (See tips for talking with family and friends about brain injury on page 58.)

Help with Medical Equipment

Some organizations loan or offer help with setting up medical equipment. See page 66 for more information.

> *“Focus on the individual’s strengths, their personal goals and visions. Always build on the positive.”*

Accessible Rideshare

Some rideshare programs offer services, including wheelchair-accessible vehicles, to help with non-emergency transportation to medical visits, as well as grocery and prescription deliveries. Ask your insurance or care provider about coverage for this service.

Types of questions to ask rehabilitation staff before discharge

Discharge timing

☐ Who decides when my child is ready for discharge from a rehabilitation program and how is that decision made?

☐ What can I do if I disagree with the decision to discharge my child from the program?

☐ What factors can affect when my child is discharged from the program?

☐ How much advance notice will we be given that my child is being discharged?

Care after leaving a rehabilitation program

☐ What are the different care options available to my child upon leaving a rehabilitation program?

☐ What happens if the care option that is best for my child is not currently available?

☐ What can we do if we are unable to make our home ready to meet the care needs of our child?

☐ Where should my child get follow-up care? What type of specialists should they see? (See pages 35-36)

☐ Where can I get a list of resources for support in my community, like my local brain injury association, case management, and home-based care?

☐ How can I help my child return to school? (See pages 47-49)

☐ Is there information or training to help me learn how to:
- Use the feeding tube?
- Manage medications?
- Assist with any physical or cognitive therapies?
- Set up my home?

☐ What things do I need to watch for that I should report to the rehabilitation team or require emergency care?

Keeping records

☐ How do I get a complete set of my child's medical records?

☐ Is there a charge for getting medical records?

When a child is unable to return home for care (alternative residential placements)*

Some children are unable to return home following discharge, either temporarily or permanently. For example, a family may not be able to meet the care needs required for the child due to family, social, financial, or cultural issues. In these situations, alternative residential placements may be appropriate. Use and availability of these services vary by state. The medical needs of a child in alternative residential placements are directed by medical professionals. In general, people under 22 are not placed in programs for adults. However, in some states, it is possible to get a waiver to allow children in some adult programs.

Examples of alternative residential placements for children may include:

Skilled nursing facilities (SNF)

SNFs (also known as nursing care facilities) provide care in specialty-licensed units of hospitals, nursing homes, or as a standalone residential facility. A SNF may be an appropriate option for individuals with brain injuries who have had extensive inpatient rehabilitation yet need more care and assistance than is available through home health services or community-based programs. Rehabilitation therapies and nursing care are provided at SNFs. The primary goal of care at an SNF is to maintain and improve function, which generally occurs at a slow rate over a long period.

Intermediate Care Facilities (ICF)

ICFs provide beds, meals, and skilled nursing care for children who have disabilities but do not need the level of care offered in a hospital or an SNF.

Transitional facilities

In general, transitional facilities are designed for children who need skilled nursing support after being discharged from the hospital but before they are ready to return home.

Residential schools

Residential schools can be public or private institutions. They are designed with special educational curriculum to meet the needs of children with a variety of disabilities and other health conditions.

Medical group homes

Medical group homes are single-family homes in residential neighborhoods in which a group of children (with varying disabilities and health conditions) live together and receive supervision and care. The amount of medical care available varies between medical group homes.

> *“It feels like the role of caregiver hovers over everything, and I must periodically escape to find the other parts of myself. Depending on what’s going on, that escape can look like walking the dog or an afternoon with my youngest granddaughters.”*

*Content was adapted from: the *American Academy of Pediatrics Clinical Report, Out-of-Home Placement for Children and Adolescents With Disabilities published in Pediatrics*

Where can I find a medical professional who specializes in brain injury?

Finding the right care for your child after a brain injury may feel overwhelming. We understand how stressful this can be. We've put together some tips to help you get started.

- ✓ Contact your local Brain Injury Association of America state affiliate or chapter (see pages 72-73) or the **National Brain Injury Information Center at 1-800-444-6443**. They may offer **neuro-resource facilitation** or have a list of medical professionals with experience in caring for children with brain injury.

Neuro-resource facilitation is a free program offered in some states. This program may:

- Help you find experienced brain injury professionals in your area
- Coordinate communication between you and your child's medical team
- Assist with Medicaid or insurance paperwork
- Help find community services and support groups
- Provide guidance on return to school or work

- ✓ Review a list of Brain Injury Medicine-certified physicians at www.abpmr.org/physiciansearch/search. These physicians have received special training in brain injury treatment and management.
- ✓ Ask your regular medical professionals, such as your child's pediatrician, about getting a referral to a brain injury specialist or services in your local area.
- ✓ Talk to others who have experience with brain injury. In-person and online support groups are a good way to get advice and find people who can link you to medical and health professionals.
- ✓ Consider using telemedicine or telehealth services (when appropriate) if you are unable to visit a medical professional in person or if brain injury professionals are not available in your local community.

Medical and Health Professionals

Below are examples of some of the medical and health professionals you may encounter during your brain injury journey and how to find them. However, the best option for finding a medical professional with experience with brain injury care is through your state Brain Injury Association affiliate or chapter or by calling the National Brain Injury Information Center at 1-800-444-6443.

Physiatrists

Search this list from the American Academy of Physical Medicine and Rehabilitation: https://members.aapmr.org/aapmr/aapmr_finder.aspx

Neurologists

Contact the American Academy of Neurology: www.aan.com/about-the-aan/contact-us

Neuropsychologists

Search this list from the American Academy of Clinical Neuropsychology: https://theaacn.org/directory/

Neuro-ophthalmologists

Search this list from the North American Neuro-ophthalmology Society: www.nanosweb.org/i4a/memberDirectory/index.cfm?directory_id=3&pageID=3390

Neuro-optometrists

Search this list from the Neuro-optometric Rehabilitation Association: https://nora.memberclicks.net/find-a-provider#/

Neuropsychiatrists

Search this list from the American Psychiatric Association: https://finder.psychiatry.org/s/

Neurosurgeons

Search this list from the American Association of Neurological Surgeons: www.aans.org/patients/find-a-neurosurgeon/

Pulmonologists

Contact the American Thoracic Association: https://site.thoracic.org/about-us or the American College of Chest Physicians: https://www.chestnet.org/

Speech-language pathologists

Search this list from the American Speech-Language-Hearing Association: https://www.asha.org/profind

Vocational rehabilitation counselors

Search this list from the Rehabilitation Services Administration: https://rsa.ed.gov/about/states

Aquatic therapists, occupational therapists, physical therapists, recreational therapists, and respiratory therapists

Search this list from the American Physical Therapy Association: www.choosept.com/find-a-pt

Chapter 4

Caring for Your Child at Home

A family's role

For many children, their brain injury journey will include care at home. A family's role in care at home will differ from child to child but may include providing daily care or supervision. You may also:

- Use community-based programs.
- Need to manage common brain injury symptoms (see pages 40-43 for more information).
- Deal with changes in family dynamics and responsibilities (see pages 57-59 for more information).
- Take an active role in recovery planning and therapies.

Community-based programs

Some hospitals and rehabilitation programs provide rehabilitation therapies within the home for children with brain injury. Be sure to check to see if costs for these programs are covered by Medicaid or your medical insurance.

Community re-entry

Community re-entry is a community-based treatment program generally focused on developing higher level motor, social, and cognitive skills in order to prepare the person with a brain injury to return to independent living and potentially to school or work. Treatment may focus on safety in the community, interacting with others, goal setting, and money management skills. Vocational evaluation and training may also be a component of this type of program. Children who participate in the program typically live at home.

Day treatment

Day treatment, also called day rehab or day neuro, involves rehabilitation care in a group setting. The focus is on developing and improving body movement, as well as thinking, memory, and social skills to allow a person to live independently. Work training programs may also be included.

Takeaways

- Community programs may be available in your area to help your child build skills and meet their care needs.
- There are several strategies and treatments families can use to help manage many common brain injury symptoms.
- Planning and support can help your child to achieve greater independence and become productive members of their communities as they age into adulthood.

Home health services

Home health services typically include physical, occupational, and/or speech therapies along with a part-time home health aide (sometimes as little as one hour, twice a week), skilled nursing services, and nutritional counseling. A social worker may arrange for short-term counseling, community support, as well as assistance with living arrangements, finances, and long-term planning based on a person’s needs.

Outpatient rehabilitation

Outpatient rehabilitation usually begins with intensive care (up to several hours a day, five days a week) then slowly decreases as a person with brain injury regains skills. Examples of activities may include physical therapy, occupational therapy, counseling, vocational rehabilitation, and speech-language therapy. These services may be provided at the hospital or at a community-based facility.

Exercising the brain (cognitive stimulation)

Cognitive simulation activities are designed to help the brain build new connections and pathways. There are simple and effective cognitive stimulation activities that you can do at home to help your child after a brain injury. Some examples include:

- Doing puzzles.
- Playing cards and board games.
- Coloring and drawing pictures.
- Reading stories.
- Clapping to rhythms when listening to music.
- Playing with clay and stacking building blocks.

See page 55 for information on brain health.

> *“Our humor regarding all things was beneficial. Instead of being frustrated when he would mis-speak or mis-label, we would find humor and it would reduce the stress of the situation. He knew he was safe to error. He would giggle or laugh instead of being embarrassed.”*

Checklist:
Caring for Your Child at Home

You can review and update this list based on your child's needs and changes in their recovery.

Home safety

☐ Remove fall hazards (loose rugs, clutter, cords, poor lighting).

☐ Install grab bars in bathrooms and railings on stairs.

☐ Use non-slip mats in showers and bathrooms and stair gates at the top and bottom of stairs.

☐ Consider adaptive equipment (shower chair, raised toilet seat, bed rails, wheelchair ramp, walk-in bathtub).

☐ Label rooms, drawers, or other household items.

☐ Lock away sharp objects, cleaning supplies, or medications (when appropriate).

☐ Post emergency numbers in a visible spot.

Medical needs

☐ Use a medication tracker, pill organizer, blister packs, or medication alarms.

☐ Hang a whiteboard calendar or use phone reminders for medical and therapy appointments.

☐ Set up and learn how to use any necessary medical equipment.

☐ Have a blood pressure cuff, thermometer, and other monitoring tools on hand.

☐ Learn first aid and have a first aid kit with seizure instructions (if relevant).

☐ Install a backup power source for medical equipment (if used).

☐ Create a plan for managing behavioral changes or crises.

☐ Have a "go bag" in case of emergency medical visits.

Daily care

☐ Create a routine or schedule to help provide structure for your child.

☐ Keep a journal or log to track symptoms, mood, sleep, and therapy progress.

☐ Look into meal delivery options or recipes for easy-to-make meals and snacks.

☐ Use adaptive utensils or cups as needed.

☐ Keep to a consistent sleep schedule.

☐ Plan for daily activity (short walks, stretching) if approved by the medical team.

Emotional and social support

☐ Participate in support groups with other caregivers (in-person or virtual).

☐ Do relaxing activities and schedule time with friends and loved ones.

☐ Establish a back-up plan if you are unable to provide care for your child.

> *"We moved furniture and rugs so there is a clear path for walking, keeping a chair in the kitchen for rest when needed, borrowed equipment from my local DME closet such as a shower bench, and adjusted our smartphone, TVs, and computer to dark mode."*

Managing some common brain injury symptoms

Brain injury may affect all aspects of a child’s life. While managing ongoing symptoms can be challenging, many children adapt and lead fulfilling lives. Supportive relationships, effective coping strategies, and engaging in meaningful activities can improve your child’s well-being. It is important to focus on what enhances quality of life, not just the difficulties your child faces.

There are several strategies and treatments that may be used to help manage many of the common symptoms. As a quick refresher, in this guide we placed brain injury symptoms into four groups:

1. Thinking and learning
2. Physical health and communication
3. Emotion and mood
4. Behavior

Thinking and learning

Many children with brain injury experience challenges with thinking and learning. These symptoms may be due to the type or location of the brain injury. However, another reason a child may experience symptoms that affect thinking and learning is due to neuro fatigue or a “tired brain.” After a brain injury, the brain may need more rest than before to recharge. You may even notice that your child is better able to pay attention earlier in the day and then become angrier or frustrated in the afternoon or evening. This is because their brain can’t manage as much information as it could before.

A child may also have trouble paying attention, making it harder for them to focus and process information. Too much stimulation in the environment, such as noise, bright lights, loud music, or large crowds of people, can cause a child with a brain injury to feel overloaded.

Tips for families

Help with organization and structure

- ✓ Create a routine or schedule—that includes rest breaks—to help provide structure for your child.
- ✓ Do more challenging thinking and learning activities in the morning or after a rest break.
- ✓ Have your child write down information (if appropriate for their age and ability).
- ✓ Hang a whiteboard calendar and use phone reminders to help keep them on task.
- ✓ Create designated quiet spaces for relaxation and to prevent overstimulation.
- ✓ Utilize memory aids like planners, notes, alarms, and smartphone apps to assist with daily tasks, appointment reminders, and medication management.

Use visual and verbal cues

- ✓ Create signs, labels, or memory books with pictures and short descriptions of people, places, and objects.
- ✓ Post safety plans for emergencies, such as a fire.
- ✓ Add labels to things like drawers and cabinets.

Manage types of activities

- ✓ Avoid or limit activities that include bright lights, loud noises, and crowded places.
- ✓ Plan short activities to prevent fatigue or frustration.
- ✓ Assist with starting an activity and provide reminders on steps to complete activities.
- ✓ Divide complex tasks into smaller, more manageable steps to reduce frustration and promote a sense of accomplishment.
- ✓ Give your child extra time to adjust if there is a change in their routine or to their regular daily activities.

Physical health and communication

There are several treatments available to help manage physical symptoms after a brain injury. Some treatments may include physical therapy and exercise, vision and vestibular therapies, stretching, medications, and the use of devices to help with mobility.

> *“I made a weekly and a monthly planner that I make notes in for tasks, doctor appointments & bill payment dates. I also set daily alarms in my phone for myself to notify me of things that I need to do at certain times.”*

Tips for families

Keep track of symptoms

√ Use a journal or log to track symptoms, mood, sleep, and therapy progress.
√ Write down what activities make symptoms worse and share this information with your child’s medical team.

Communicate clearly

√ Break down information and instructions into simple steps.
√ Give your child time to respond and process information.
√ Use short sentences and hand gestures.
√ Ask “yes” or “no” questions when possible.
√ Make eye contact when speaking to your child.
√ Alert your child to changes in conversation topics.

Establish healthy behaviors

√ Ask for a physical activity routine from your child’s medical team.
√ Eat nutritious foods to support overall well-being.
√ Keep to a consistent sleep schedule.
√ Only give your child medications recommended by their medical team.

Explore equipment and technologies

√ Reduce the chance for falls by having your child use a walker or wheelchair if they need assistance with mobility.
√ Look into the need for glasses (such as prism lenses) to help with vision problems.
√ Use lifts or other devices to assist with moving your child.
√ Consider electronic devices that help with communication.

Emotion and mood

Depression and feelings of sadness and hopelessness can affect both a child with a brain injury and their loved ones. These feelings are common, especially due to the stress children and their families often experience during the brain injury journey. However, if you or your child experiences these feelings for weeks, months, or longer, it is important to talk with a mental health professional. Mental health professionals have treatments that can help.

Tips for families

Watch for ongoing and worsening symptoms of depression

- ✓ Call 988 and seek medical care right away if you or your child has thoughts of suicide, or plans or attempts suicide.
- ✓ Seek help from a mental health professional if you experience or notice the following symptoms of depression in your child:
  - Changes in appetite, including eating or drinking too much or having no appetite.
  - Fatigue or lack of energy.
  - Feeling sad, hopeless, and having trouble getting through the day.
  - Feelings of worthlessness, guilt, or that you are a failure.
  - Difficulty concentrating.
  - Loss of pleasure in activities that were once enjoyable.
  - Sleep problems, like sleeping too much or being unable to sleep.

Explore social and physical activities

- ✓ Join a support group.
- ✓ Do things that provide comfort, such as spending time in nature or with animals.
- ✓ Schedule time for yourself and your child to be with family and friends.
- ✓ Participate in hobbies that you both enjoy and consider exploring new hobbies.
- ✓ Do activities outside, like taking walks (if approved by the medical team).

Keep to a regular sleep routine

- ✓ Sleep in a dark, cool room.
- ✓ Keep to a set bedtime routine with fixed sleep and wake up times as much as possible.
- ✓ Create a relaxing bedtime routine.
- ✓ Avoid screen time, loud music, large meals, and caffeine right before bed.

Encourage your child to express their emotions

- ✓ Acknowledge their feelings.
- ✓ Let them share their feelings without judgment.
- ✓ Look for opportunities for them to express their feelings through activities, like art, writing, and music.
- ✓ Remind them that it is normal to have ups and downs during their brain injury journey.

Behavior

Behavioral challenges, including problems with social skills and interactions with others, are some of the most challenging symptoms for caregivers to manage after a brain injury. Aggression toward others, self-injury, property destruction, yelling and cursing, or doing inappropriate things may lead to serious concerns and stress on families. Oftentimes, behavior problems are the result of challenges with processing information or understanding situations correctly. Early on, some children may experience a period of anger or agitation. While this may be concerning, it is generally a sign that the brain is healing. It usually goes away as the brain begins to heal. However, if difficulties with processing or understanding situations continue, agitation can remain.

Your child may not understand the changes that have occurred and may make statements like, "I'm fine," or "My memory is fine." Behavior changes may increase among children aging into adolescence. Part of the brain injury journey is helping your child understand the effects of the injury. These effects may include the inability to recognize changes in one's skills and capacity, or problems with self-awareness.

These issues can result in impaired judgment, compromised safety due to unrealistic goals, and decreased motivation to work on problem areas. Parents know their children better than anyone and should share any concerns with medical professionals.

Tips for families

Practice self-care

✓ Take care of yourself, being a caregiver is hard.
- Get enough sleep.
- Eat well.
- Exercise (even if that means just taking short walks).
- Ask for and accept help from others.

Use behavioral strategies

✓ Try to remain calm and avoid arguing with your child if they become angry or agitated.

✓ Show your child how to do a task before they attempt it and then let them try things and make mistakes.

✓ Redirect your child's attention to something else.

✓ Give praise for good behaviors and limit focus on poor behaviors.

Look for ways to lower stress

✓ Do deep breathing exercises with your child.

✓ Provide a place for your child to take quiet rest breaks as needed.

✓ Encourage your child to talk about their feelings (if appropriate for their age and ability).

Ask for help

✓ Request help from your child's medical team on how to handle outbursts and challenging behaviors.

✓ Be sure to update your child's medical team on symptoms that get worse.

✓ Report any safety concerns to the medical team right away.

Check out additional resources from BIAA

✓ *Coping With Behavior Problems After Brain Injury* by Claude Munday, PhD, William Lynch, PhD, John Haller, and Carol Welsh, MPA, CBIS. https://biausa.org/public-affairs/media/coping-with-behavior-problems-after-brain-injury

✓ *Behavioral Issues After a Brain Injury: Strategies for Families,* a webinar by Chrystal Fullen, PsyD, as part of BIAA's Carolyn Rocchio Caregiver webinar series. https://biausa.org/public-affairs/media/behavioral-issues-following-brain-injury-strategies-for-families

Emotional support, service, and therapy animals

Emotional support, service, and therapy animals can make a meaningful difference for some families. Studies show that animals can provide companionship, help with daily tasks, encourage feelings of confidence and independence, have a calming effect, and may improve attendance at therapy appointments.

Type of support animal	What they do	Considerations	How to find one
Emotional suppport animals	An emotional support animal provides comfort through companionship. Generally, no special training is needed.	An emotional support animal may not be allowed in public places, like restaurants, stores, and schools.	An emotional support animal may be adopted through various sources, such as a shelter or animal rescue organization.
Service animals	A service animal is trained to perform a task directly related to a person's disability, such as providing disability support or detecting the onset of a seizure.	A service animal is protected under federal law. They are allowed in public places like schools, stores, and airplanes.	Service animals may be found through an accredited training organization. There may be a waiting list to get a service animal.
Therapy animals	Therapy animals accompany their owner to visit places like hospitals and schools to comfort people.	Therapy animals are not personal pets.	Therapy animals are generally part of volunteer and community programs. Contact your local brain injury association or your child's medical or rehabilitation team about local programs.

Things to do before bringing home an animal

- ✓ Be sure your child is comfortable around animals.
- ✓ Decide what type of animal is a good fit for your child and their needs.
- ✓ Meet the animal before adoption/training begins.
- ✓ Consider the time and costs of having an animal at home, including veterinary care.
- ✓ Contact an organization that specializes in training animals (if training is needed).

Aging into adulthood

Most parents can agree that childhood moves fast and caring for a teen adds new challenges and concerns. During this time, families need to balance a teen's desire for independence with their ability to make responsible decisions regarding their health, safety, and future school and career goals.

For a teen living with a brain injury, the path to adulthood may be unique and include additional challenges and steps. However, with the right planning and support, families can help prepare their teens to achieve greater independence and become productive members of their communities.

Involve your teen in planning and get started early

Federal law requires that schools create a plan that helps teens aged 14 and older living with disabilities prepare for life after high school. For some, this may mean planning to attend college, while for others the plan may focus on helping them enter the workforce or find volunteer and community activities.

A plan for life after high school should:

- Be based on your teen's interests, personality, and abilities
- Include input from your teen
- Discuss any needed changes to formal support services, such as:
    - Changing from an IEP to a 504 plan
    - Updated accommodations and goals
- Explore future options for educational programs
    - University
    - Community college
    - Trade schools
- Provide opportunities for:
    - Use of state vocational rehabilitation services
    - Internships or job coaching
- Include life skills training on:
    - Money management
    - Meal planning and cooking
    - Transportation needs
    - Household tasks
    - Time management and self-care
- Outline social and mental health support
    - Counseling or therapy
    - Peer support groups
    - Social skill-building programs

Focus on continuing care for health needs

Studies suggest that use of medical and healthcare services for brain injury drops as teens age into adulthood. This can affect their progress and lead to worse health outcomes.

A plan for managing healthcare should:

- Focus on building their confidence in managing their care, including:
    - Medication management
    - Scheduling appointments
- Manage the change from the pediatric to adult healthcare setting, including
    - Input from your teen
    - Feedback from medical professionals
    - Information on the importance of follow-up care
- Plan for independence
    - Create a healthcare binder that includes their previous medical history
    - Make your teen aware you may not be able to access medical records or receive communications from medical professionals once they turn 18
- Consider legal and financial issues
    - Healthcare coverage
    - Guardianship or supported decision-making
    - Power of attorney (medical and financial)
    - Special needs trusts
    - ABLE (Achieving Better Life Experience) accounts

Chapter 5 Getting back to activities

Starting regular activities

Experiencing a brain injury can bring about a wide range of symptoms that can affect daily life and overall well-being. Getting back to school, work, or other daily activities are big milestones for many families during the brain injury journey. Be sure to ask your child's medical professional for help and guidance on when and how to help them:

- Return to school.
- Get physically active.
- Enter or re-enter the workforce.

Returning to school

Returning to school after a brain injury is an important part of your child's recovery. Most children can and should return to school or academic activities after a brain injury. Participating in school and other academic activities helps them:

- Stay connected and make friends.
- Build or re-learn skills.
- Keep a routine.
- Do physical activities.
- Prepare for adulthood.

Brain injury symptoms may make it harder for some children to attend school or do their schoolwork. It is important to set up a plan to help lessen or prevent symptoms from getting worse at school. Schools can provide supports and make academic adjustments that are designed for specific brain injury symptoms and help your child ease back into schoolwork. School supports and academic adjustments are provided primarily to assist with learning and achievement rather than to restore a child's school performance to what it was before the brain injury.

Notifying the school about your child's brain injury

You should notify the school right away about your child's brain injury. Ask your child's medical professional for written information to share with school professionals about your child's injury, symptoms, medical needs, and when they should return to school. See pages 50-51 for an example school letter from a medical professional. To get

Takeaways

- Helping your child get back to school and other daily activities are important steps in the brain injury journey.
- There are supports and programs available to help your child achieve academic success, enter the workforce, and get active in their community.
- Friendship and positive social activities are good for your child's mental health.

information on your child's brain injury sent to the school from their medical professional, you may need to sign a medical release form. Another option is to make copies of your child's medical records and share them directly with the school. Be sure to request that information about your child's brain injury is placed in their comprehensive educational file and student health record.

Ask your child's school to create a plan

If a child attends a public school (or charter school), getting a return-to-school plan in place often starts when a parent or guardian writes an email to the school's principal, vice principal, nurse, teacher, and/or counselor that shares information about the child's injury and asks for an evaluation for special education services under the Individuals with Disabilities Education Act (IDEA). When a child's health condition is reported to the school, school professionals are required to evaluate and create a plan for managing the health condition while the child is in school. This process does not automatically enroll a child into the special education program. Instead, it serves as a pathway to access additional supports or academic adjustments that can be approved and put in place.

In general, a plan should:

- Identify a case manager who will serve as the primary point of contact for everyone (including school professionals, medical professionals, and parents).
- Outline who is responsible for monitoring your child while they are at school.
- Consider your child's age, symptoms, level of understanding, and emotional status.
- Include the type and length of activities your child can handle.
- Address any schoolwork they may have missed.
- Be made available to any of the school professionals who interact with your child at school.
- Include feedback from you and your child (if appropriate for their age and ability).

> *“I meet with my child's teachers to go over his accommodations so they understand his needs and we are all on the same page and know they can reach out me.”*

Setting up an Individualized Health Plan (IHP) or Individualized Health Care Plan (IHCP)

IHP and IHCPs are formal documents created by the school nurse (or whoever oversees medical/health-related issues at school). These documents vary by state, but in general, they outline a child's health conditions and how to manage them while the child is at school. As an example, a child's IHP or IHCP may include how and when they should take medications for seizures and headaches during the school day. If your child's school sets up an IHP or IHCP, be sure that it includes input from you and your child, as well as from their school nurse, medical professional, and other school professionals your child interacts with during the school day.

It is important to send reminders and ask for updates on the status of your child's return-to-school plan to make sure the process moves forward.

Types of school supports and academic adjustments

Federal law requires that public schools provide support to children identified as having short- or long-term disabilities due to a brain injury. The type of formal support will differ depending on the specific needs of each child. You can request a meeting with school professionals to discuss what types of school supports and academic adjustments are best for your child. You can also request that your child be evaluated by the school if you have concerns about your child's learning due to ongoing symptoms of brain injury.

The following are summaries of common educational supports available through schools. Importantly, these services may vary by state and school district. Many states offer special education services to people until age 22, but some states have extended eligibility through to age 25.

Informal academic adjustments

If your child's brain injury symptoms are expected to get better and not affect them for more than a couple of weeks, their school may recommend informal academic adjustments. Informal academic adjustments are designed to help a child re-enter and succeed in school, but there are no changes to academic standards, school content, or requirements.

Multi-Tier System of Support (MTSS) or Response to Intervention Protocol (RTI)

An MTSS or RTI may be used for students who need academic adjustments for an extended period and/or need to increase the level of a particular intervention. An RTI allows for a multi-step, targeted approach that school professionals can use to monitor a student's progress through increasing levels of intervention. At each intervention level, a school professional assesses the students to determine whether additional instruction or support is needed.

504 Plan

Students with long-term or persistent symptoms and who require assistance to be able to participate fully in school may be candidates for a 504 plan. A 504 plan removes barriers and provides support that allows a student with disabilities to learn alongside their peers in the classroom. For example, a 504 plan for a child with brain injury might include environmental adaptations, behavioral strategies, or learning supports such as extra time for classwork and testing in a separate room. However, the curriculum cannot be modified under a 504 plan.

A 504 Plan is a legally binding document. To qualify, the school generally:

- Collects data and evaluates the child to determine if he/she has a physical or mental problem that substantially affects a major life function (such as learning, thinking, reading, or sleeping).
- Requires medical documentation of a brain injury from a medical professional.

Individualized Education Program (IEP)

Children with brain injury who require significant help to participate in the school curriculum, that cannot be managed by a 504 plan alone, may be eligible for an IEP. An IEP is part of special education and it details the special education and related services that a school will provide to meet the unique needs of a student with a disability. An IEP may include adjusting the student's curriculum, adjusting methods or pace of instruction, or allowing the student to work in a smaller classroom environment other than an inclusive classroom. To qualify for an IEP, a school will evaluate the child through a psycho-educational evaluation.

Child Find is part of IDEA. It requires that every state and its public schools have policies in place to identify children (up to age 21) in need of special education and related services.

Special education services for infants, toddlers, and preschool-age children

If your child is under age 5, you can request that your local Early Intervention Program evaluate your child. Public schools are required to provide qualifying services to infants and toddlers who demonstrate developmental challenges through an Individual Family Service Plan. Once a child reaches age 3, and if they qualify for an IEP, they can get services from their local school district as part of the early childhood education program.

Considerations for private school students

If your child attends a private school, be sure to check with the school to see if they offer special education services. School districts may set up a private school service plan. However, the services may be more limited than what's offered in a public school.

Ask your child's medical professional to fill out this handout. You can then share it with your child's school to help with return to school planning.

Dear School Staff:

This letter is to update the school on ______________________________________

who sustained a brain injury on ______________________. This letter offers input to help school professionals support students returning to school after a brain injury. You can use this information to make decisions about support for the student based on their specific needs. This letter is not intended to create a 504 plan or IEP unless school professionals determine that one is needed.

The student is currently experiencing or reporting the following symptoms checked below:

Thinking and learning

☐ Difficulty understanding, thinking clearly, or problem-solving
☐ Trouble learning skills
☐ Problems concentrating or paying attention
☐ Difficulty remembering or processing information
☐ Inability to start tasks (changes in motivation)
☐ Easily distracted or unable to shift focus

Physical health and communication

☐ Headaches
☐ Weaknesses in arms and legs
☐ Problems with coordination, balance, hearing, or vision (including sensitivity to light or noise)
☐ Bladder and bowel trouble
☐ Changes in sensory perception, such as smell and touch
☐ Difficulty speaking and communicating
☐ Trouble with sleep (sleeping more or less than usual)

Emotion and mood

☐ Feeling more emotional than usual
☐ Nervousness or anxiety
☐ Sadness, depression
☐ Sudden crying or laughing for no clear reason

Behavior

☐ Trouble controlling behavior
☐ Personality changes
☐ More impulsive than usual
☐ More angry or aggressive than usual
☐ Poor judgment and risk-taking

Other symptoms the student is experiencing or reporting: ________________________

____

____

____

____

Based on the student's current symptoms, I recommend that the student:

☐ Is permitted to return to school and activities while school professionals closely monitor the student. School professionals should observe and check in with the student for the first two weeks and note if symptoms worsen. If symptoms do not worsen during an activity then this activity is OK for the student. If symptoms worsen, the student should cut back on how much he or she does that activity and may need some short term support at school.

☐ Is excused from school for ____________ days.

☐ Return to school with the following changes until their symptoms improve.
Based on the student's symptoms, please make the short-term changes checked below:

☐ No physical activity during recess

☐ No physical education (PE) class

☐ No after-school sports

☐ Shorten school day

☐ Later school start time

☐ Reduce the amount of homework

☐ Postpone classroom tests or standardized testing

☐ Provide extended time to complete schoolwork, homework, or take tests

☐ Provide written notes for school lessons and assignments (when possible)

☐ Allow for a quiet place to take breaks throughout the day

☐ Lessen the amount of screen time on computers, tablets, etc.

☐ Give ibuprofen or acetaminophen to help with headache (as needed)

☐ Allow the student to wear sunglasses

☐ Allow the student to wear ear plugs or headphones

☐ Other: ______________________________

____

____

If there are any symptoms that concern you or are getting worse, notify the student's parents that the student should be seen by a healthcare provider as soon as possible.

Medical professional name (printed) ______________________________

Medical professional signature ______________________________

Date ______________________________

For additional questions you can reach me at: ______________________________

Entering (or re-entering) the workforce*

Children as young as 14 can be employed in some states. It may take time, but many children living with brain injury can find their first job or return to work and have fulfilling careers. Talking to your child's medical professional is a good place to start when your child is ready to begin a career. A medical professional may refer your child to a brain injury professional who can do tests to assess what type of employment may be a good fit for them based on their personality, skills, abilities, and interests. Many rehabilitation facilities (particularly transitional or community reentry programs) can help share employment options and help your child build skills to enter or re-enter the workforce.

Career One Stop (www.careeronestop.org) is provided through the Department of Labor to help link people, including those living with disabilities, with employment and training programs.

You can find disability-friendly employers by searching specialized job boards like www.abilityjobs.com or www.usa.gov/find-a-job.

Getting supports or accommodations

Under the Americans with Disabilities Act (ADA), only employers who have 15 or more employees are required to provide what are considered "reasonable" accommodations. Even so, some state and local laws may also require that employers with fewer employees provide reasonable accommodations. ADA considers a reasonable accommodation as:

"Any change to the application or hiring process, the job, the way the job is done, or the work environment that allows a person with a disability who is qualified for the job perform the essential functions of that job and enjoy equal employment opportunities."

An employer is not required to put accommodations in place that may cause harm or challenges to the company or business. To set up reasonable accommodations, your child would need to:

- Share information about their disability with their employer.
- Send an email to their employer to request accommodations under the ADA. Providing examples of requested accommodations is recommended.

In response, an employer may request documentation about their disability from a medical professional.

Ticket to Work program

Social Security offers a work incentive called Ticket to Work program under which a person can work for nine months (within a rolling 60-month period) without loss of benefits. Arrangements can also be made to continue Medicare coverage even when Social Security disability benefits are ended. You can learn more about this program at www.choosework.ssa.gov.

Organizations that can help

There are several types of organizations that can help your child enter the workforce after a brain injury. Two examples include:

- **State Vocational Rehabilitation (VR) Agencies:** These programs are funded by both federal and state governments and help people with disabilities prepare for, find, and keep employment. They offer a range of services, including vocational evaluations, job coaching, and help with job placement.
- **The Job Accommodation Network (JAN):** JAN is a free resource that provides expert guidance on workplace accommodations and disability employment issues. They can offer advice on specific accommodations that can help a person with a brain injury succeed in their job.

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*Content was adapted from the article, *Entering or Re-entering the Workplace After Brain Injury* by Carolyn Rocchio. Get more tips in BIAA's free webinar series for caregivers at https://biausa.org/brain-injury/community/caregiver-information-center.

Physical activity and sports

Physical activity is good for overall brain health. When approved by their medical professional, your child can ease back into physical activities. Your child should only do physical activities that do not put them at risk for another injury to the head or brain during their recovery. Most children start their physical activity routine by taking short walks. Be sure to watch for changes in your child's symptoms as they begin physical activities. If their symptoms get worse, it is important to cut back on that activity.

Guiding the recovery of individuals of any age with a brain injury who participate in competitive or recreational activities requires careful management to avoid another brain injury or prolonged recovery. Ask your child's medical professional for written information on the Return to Sports Progression and share this information with school professionals and coaches who interact with your child during the day. The Return to Sports Progression, based on the International Consensus Statement on Concussion in Sport, involves six steps that a child works through gradually. The Return to Sports Progression is best done using a team approach and with guidance from a medical professional, such as an athletic trainer, who knows the child's physical abilities and endurance. By gauging the child's performance on each individual step, a medical professional will be able to determine how far to progress the child on a given day. In some cases, the child may be able to work through one step in a single day, while in other cases it may take several days to work through an individual step. It may take weeks to months to work through the entire progression.

Adaptive sports

You can find adaptive sports and activities through national organizations like Move United and BlazeSports America.

Driving after brain injury

Brain injury can affect the many physical, thinking (such as attention and concentration), and behavioral skills required to drive safely. It is common for individuals with brain injury to feel as though they are ready to drive, while family members have serious concerns. If your child is old enough to have a driver's permit or license, driving evaluations are crucial in determining their ability to drive safely. Evaluations can serve as important reality checks when people overestimate their driving abilities. If your child is unable to drive, exploring rideshare or public transit options may be helpful. Many rehabilitation facilities offer driving programs for a fee.

Volunteering

Volunteer opportunities have many benefits for a person's overall well-being. There are opportunities for your child to get involved in their community's volunteer efforts. Your local brain injury association, Goodwill Industries, Easter Seals, Catholic Community Charities, Jewish Family Services, and many other organizations offer opportunities for people living with a brain injury to use their skills and participate in the community.

> *“Stay positive, go slow.*
> *Take one day, one hour,*
> *one minute at a time.”*

Friendships and social activities

Friendship and social activities are a big part of life for most children. The need for these activities often doesn't stop after brain injury. A child may feel sad or lonely if they are unable to connect with their peers. It may take time to build relationships. Other children and parents may not understand brain injury or be patient with brain injury symptoms. However, there are mental health benefits to social interactions with others.

Tips for families

- ✓ Choose social activities that your child can participate in and enjoy. Remember that the activities they used to do may be difficult now that they are living with a brain injury. You may have to try new activities or make adjustments to activities they participated in before their injury.
- ✓ Explore hobbies and interests that fit your child's age and abilities. This could involve engaging in adaptive sports and activities.
- ✓ Keep a schedule for social interactions. Set reminders to call or text people.

Dating after brain injury

As your child enters high school, dating may gain more importance. Dating with a brain injury can present unique challenges, but it's possible for your child to build fulfilling relationships after a brain injury.

Things to consider:

- It helps to take it slow and get to know someone and build trust before your child shares details about their brain injury.
- People with disabilities are at risk of getting caught in online dating scams. Keep an eye out for red flags, such as a person asking for money for an emergency.
- Some children may be more impulsive or engage in inappropriate sexual behaviors, including unwanted hugs, kisses, and flirtatious advances. Ask their medical team for help with managing these behaviors. You can also **call the National Brain Injury Information Center at 1-800-444-6443** or check out BIAA's website for resources on this topic.
- Brain injury can affect communication and emotional expression. Talk to your child about being open and honest about their needs and challenges.
- Look into therapy if your child needs help with emotional control and coping strategies. Building a healthy relationship takes time and effort, especially after a brain injury.

Holidays and gatherings

Individuals with brain injuries and their families often become isolated due to exhaustion, embarrassment, or other emotions. It is natural for caregivers to want to avoid social situations when it is physically exhausting to maneuver a loved one outside the home or if they feel embarrassed to deal with disruptive behavior. Avoiding gatherings, however, does not benefit you, your loved one, or your family and friends.

Instead of trying to push through longer events or gatherings, plan on spending a shorter amount of time with loved ones. For example, if a family member is hosting a birthday party or Thanksgiving gathering that might last for several hours, plan to spend one or two hours—or however long your child can handle—at the event. These shorter visits can allow your child to talk and connect with other family members, then return home before becoming overwhelmed or burned out.

You can also work on creating virtual connections with friends and family. Schedule regular video calls with extended family or friends that allow your child to maintain their relationships in a more low-stress, low-stakes environment.

> *“The thing that helped me was hiring a life coach who was a TBI survivor who helped me navigate my many symptoms and medical care journey. [My life coach] also helped me stay accountable and engaged with self-care activities ... such as on going home therapy.”*

Focus on Brain Health

Brain health is for everyone—people living with brain injury and caregivers alike. It involves protecting your physical, mental, and social well-being—no matter your age.

To keep your brain healthy, medical professionals recommend:*

- ☐ Getting a good night's sleep.
- ☐ Monitoring your blood pressure and blood sugar levels.
- ☐ Eating healthy foods and staying hydrated by drinking plenty of water.
- ☐ Keeping active in physical and social activities.
- ☐ Taking steps to prevent injuries to the brain caused by a bump, blow or jolt to the head or a loss of oxygen to the brain.
- ☐ Getting regular check-ups with your medical professional, staying up to date on vaccines, and asking for mental health support when needed.
- ☐ Avoiding alcohol, smoking, and drugs or medicines not recommended or prescribed by a medical professional.

> *“Being outside in nature is very healing.”*

*Content adapted from, *“The Brain Health Imperative in the 21st Century—A Call to Action, The AAN Brain Health Platform and Position Statement,”* published in Neurology in September 2023

Chapter 6 Self- and Family-Care

Adapting to changes

When a child has a brain injury, life can suddenly change—not just for them, but for the whole family. Everyone may need to adjust their routines, roles, and responsibilities at home. For some this may be stressful and confusing, while others may feel sad or angry. It is important to watch for changes among other children in your household. Siblings may struggle with disrupted family routines. For example, they may behave differently, experience mental health problems, and/or have drops in school performance. It may take time, and there may be setbacks and challenges, but families can learn, adapt, and grow stronger during the brain injury journey.

Tips for families

- ✓ Set aside time for members of the family to talk openly about how they are feeling.
- ✓ Consider individual and/or family counseling.
- ✓ Do activities together outside of caregiver responsibilities.
- ✓ Share tasks and responsibilities based on each person's abilities.
- ✓ Schedule time to provide attention or do activities with your other children away from your caregiver responsibilities.
- ✓ Practice stress reduction techniques like deep breathing, meditation, and mindfulness to promote emotional well-being.
- ✓ Learn about brain injury and look for training opportunities to help build your confidence on caring for your child.

Takeaways

- There are things you can do for yourself and your family to grow stronger during the brain injury journey.
- Acknowledging feelings of loss and practicing self-care may lower stress and help build coping skills.
- There are opportunities for you to share your story and get involved to advance brain injury research and care.

You can check out BIAA's Brain Injury Fundamentals training and materials at **biausa.org**

Talking about brain injury*

You may get questions from family and friends about your child's brain injury. Many of these people are well-meaning as they try to understand the effects of brain injury and how your child is doing. Still, some questions or statements may be uncomfortable or stressful. For example, you may hear your child "looks fine," as the symptoms may not be obvious to others at first. "Invisible disabilities," like some brain injuries, can lead to misunderstandings between friends, family, and even medical professionals who do not recognize the challenges your child is facing because they aren't immediately apparent. Misunderstandings may harm relationships with friends and family. They can even prevent your child from getting appropriate medical care and school supports or accommodations.

Prepare yourself to talk with others

- Check out the BIAA Brain Injury Fundamentals training at www.biausa.org to learn about brain injury and better understand brain injury symptoms and recovery.
- Think about common questions, like, "What happened to him/her?" and come up with responses you feel comfortable sharing. It is OK not to answer every question you get from others.
- Try to focus on those who listen and show care. Not everyone will be supportive or helpful.
- Be honest about how you are feeling and share the challenges you are experiencing.
- Correct misunderstandings gently. If someone says something that isn't helpful, use it as an opportunity to share information about brain injury.

Feelings of loss**

You may notice or feel that your child is different after a brain injury. As a result, you may experience a sense of loss due to things like:

- Memories of your child before the injury.
- Changes in emotional connections with your child.
- Differing future expectations for your child.

These feelings are valid. It is important to give yourself permission to grieve. You may also consider:

- Writing your feelings down and sharing them with others.
- Planting a tree or hosting a remembrance ceremony as a way of marking change.
- Joining a support group to connect with others who have similar experiences.
- Talking with a grief counselor.

> *"Take one day at a time, things will and do progress through time. Don't give up hope, you're not alone."*

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*Content adapted from the Model Systems Knowledge Translation Center handout, *"Talking to People About Your Traumatic Brain Injury."*

**Content adapted from, *"Unnamed pain: Coping with ambiguous loss,"* which was written by Rich Oswald and published in Psychiatry & Psychology.

Plan for self-care

Being a caregiver is hard. It may be a 24 hour a day, seven days a week job that you balance with other family responsibilities and work. Self-care can play a role in helping you through the brain injury journey.

Some ways to incorporate self-care into your day-to-day activities include:

- **Establishing a morning and nighttime routine.** During this time, you can stretch, practice mindful breathing, meditate, journal, or just have some quiet time to yourself.
- **Making sleep a priority.** Stick to a schedule and make sure you're getting enough sleep. It's important to note that blue light from devices and screens can make it harder to fall asleep, so try to reduce blue light exposure from your phone or computer for at least an hour before bedtime.
- **Exercising each day.** You don't have to hit the gym or run a mile to feel accomplished – exercise can be achieved through yoga, taking a walk, or doing jumping jacks right in your living room.
- **Creating lists to help you stay on track.** Making lists can be calming. Some examples include planning out your goals for the week, creating a grocery list, or putting together a to-do list for the day.
- **Focusing on one thing at a time.** It can be overwhelming to think about too many things at once. Instead of thinking about long to-do lists and possible scenarios, try to focus on one thing at a time.
- **Asking for help when you need it.** Asking for help is not easy and may not come naturally to you, but it's often necessary. Whether you are asking someone to pick up groceries for you, help you remember a medical appointment, or just provide a listening ear, know that it is OK. Many people in your life will want to help you—they just may not know what you need.

> *“I call a friend once a day to make small talk. It is important, to me, to feel a sense of continuity.”*

Try affirmations

Affirmations, also called self-affirmations, are thoughts you intentionally come up with to support, encourage, and calm your brain and body. They typically consist of positive statements used to challenge negative, depressing, or anxiety-producing thoughts. You can try using some of these affirmations to help you stay positive:

- I am strong.
- I am enough.
- I have faith in my abilities.
- I am grateful for what I can do.
- I am happy to be me.
- I am on the right path for me.
- I will turn negative thoughts into positive ones.
- I honor my body by trusting the signals that it sends me.
- Though these times are difficult, they are part of the journey of life.
- One step at a time, one day at a time is progress.

Share your brain injury journey with others

You can use the handout on page 61 to connect with and join others on the brain injury journey. All you need to do is:

1. Fill in the handout.
2. Take a picture of yourself holding it.
3. Post it to social media.
   Include #MyBrainInjuryJourney
   Tag BIAA:

   Facebook: @BrainInjuryAssociationofAmerica
   Instagram: @bia_usa
   LinkedIn: @Brain-Injury-Association-of-America
   X: @biaamerica

See page 74 for a list of additional resources, including webinars for caregivers, and get to know more about BIAA.

My brain injury journey is...

My Brain Injury Journey

biausa.org/mybraininjuryjourney

Brain Injury Association of America

Appendix

Five Tips for Applying for Social Security Disability Benefits

Applying for Social Security disability benefits can be hard. The following information was created to help shed some light on the process.

1. Identify the Social Security disability program that is best for you

The Social Security Administration (SSA) has two different disability programs. You might qualify for one or both.

- **Social Security Disability Insurance (SSDI):** This is for people who have worked for a long time. If you get SSDI, you may also be able to get Medicare after about 29 months.
- **Supplemental Security Income (SSI):** This is for people who have not worked enough to get SSDI. It is for people with low income and few resources. If you get SSI, you may be able to get Medicaid right away.

> *"It can be hard to ask for help paying for medical care. But, Social Security and other government programs are there to help us when we need them. That is why they exist."*

2. Start your application early

- **Schedule an interview:** For children, the application process consists of several forms and a mandatory interview with an SSA representative. Although a portion of the paperwork can be completed online, you may complete some forms during the interview.
- **Check your work history:** You can create a free online account called "My Social Security." This account shows your past earnings and tells you if you might qualify for SSDI. It also gives an estimate of your possible payment. You can access it at https://www.ssa.gov/myaccount/what.html
- **Ask for help:** You can call SSA at **1-800-772-1213** or find your local office here: https://secure.ssa.gov/ICON/. You can also make an appointment with your local office to get help with your application.
- **Fill out the application:**

  Online: The fastest way is to apply online at https://secure.ssa.gov/iClaim/dib

  Paper: If you cannot apply online, you can print a paper application here: https://www.ssa.gov/forms/ssa-16-bk.pdf
- **Use the checklist:** Before you apply, it is a good idea to print and use the "Checklist for Online Social Security Disability Application." It helps you get all the information and papers you will need.

3. Get prepared

- **Collect required documentation:** You will need information to support the claim. Get ready by preparing records of medical appointments, physical examinations, mental examinations, records of diagnoses, treatment results, and statements from medical professionals and educators who interacted with your child.
- **Check your work history:** They will make sure you have worked enough years to qualify.
- **Review by a state office:** They will send your case to a special office that decides if your child is disabled. This office will contact you for more information and to review your application.
- **Ask about Compassionate Allowance:** If your child qualifies for Compassionate Allowance processing, you may receive a decision in as little as 10 days. If not, expect a long wait for a decision from SSA. This can take a long time, usually three to eight months.

4. Don't give up if you are denied

If your application is denied, you have **60 days** to appeal (ask them to look at it again).

Get a lawyer: You can get a lawyer to help you with the appeal. Most Social Security lawyers do not charge a fee unless you win your case. The fee is usually a small part of the money you get. The fee is either 25 percent of your back pay or $7,000, whichever is less.

How to appeal: There are four levels of appeal. You might not need to go through all of them.

1. **Get documentation:** Be sure to collect detailed medical records that outline your loved one's brain injury and related disabilities from a medical professional.
2. **Request reconsideration:** This is the first step. You can file online on the "Appeal a Decision" page. You can also print a form and mail or fax it to your local SSA office.
3. **Hearing with a judge:** If your reconsideration is denied, you can ask for a hearing with a judge.
4. **Review by appeals council:** If the judge denies your case, you can ask for a review by the Appeals Council.
5. **Federal District Court:** If the Appeals Council denies your case, you can file a lawsuit in a U.S. District Court.

5. Legal resources are available to help

You can find a lawyer by visiting www.biausa.org/preferredattorneys or through these organizations:

National Association of Disability Representatives (NADR)
Phone: 1-800-747-6131
Website: www.nadr.org

National Organization of Social Security Claimants Representatives (NOSSCR)
Phone: 845-682-1880
Website: www.nosscr.org

Medicaid Snapshot

Medicaid is a joint federal and state program that offers medical coverage for people who meet certain income requirements and/or who are living with disabilities. Each state program has its own rules about who is eligible for Medicaid in the state. Individuals must also meet certain non-financial eligibility criteria. Medicaid beneficiaries must:

- Be residents of the state in which they are receiving Medicaid.
- Be either citizens of the United States or lawful permanent residents.

Some eligibility groups are limited by age, or by pregnancy or parenting status.

Children who qualify for Supplemental Security Income benefits also automatically qualify for Medicaid. Even if your family's income no longer meets the levels required for Supplemental Security Income, your child may be able to keep their Medicaid coverage.

Managed Care Medicaid

In most states, Medicaid coverage is provided through managed care plans, where the state contracts with private companies to manage the healthcare services for Medicaid beneficiaries.

Find your state's Medicaid agency

https://www.medicaid.gov/about-us/where-can-people-get-help-medicaid-chip

Different types of Medicaid

- **Traditional Medicaid:** This is the original Medicaid program that provides comprehensive healthcare coverage, including hospital visits, doctor appointments, labs, and more. This is the Medicaid that many hospitals assist with applying for before discharge. It does not typically cover long-term services and supports.
- **Institutional Medicaid:** This program, also known as Nursing Home Medicaid, which is designed to cover the costs of long-term care in a nursing facility for individuals who require a higher level of care and meet income and asset requirements. It covers room and board, nursing care, personal care, and therapy services.
- **Long-term care Medicaid:** This type of Medicaid provides coverage for individuals who need assistance with daily living activities, such as those in nursing homes or those receiving home and community-based services.
- **Medicaid Aging and Disability Waivers:** This program, including home and community-based services or Long-Term Services and Supports (LTSS) Medicaid, provides opportunities for beneficiaries to receive services in their own homes or communities rather than institutions or other isolated settings. These programs serve a variety of groups, such as older adults, people with intellectual or developmental disabilities, people with physical disabilities, and people with brain injury.

Brain Injury or Traumatic Brain Injury Wavier

Some states provide a specific Brain Injury or Traumatic Brain Injury Wavier. These waivers include services like rehabilitation, case management, and supported employment. The scope and length of services, and age requirements, will vary from state to state.

Applying for the traditional and long-term Medicaid

Many states require people living with disabilities to submit a Social Security disability application to apply for traditional and long-term Medicaid.

- Types of home and community-based waivers vary by state.
- Every state has some type of Medicaid waiver.
- Most states have waiver services for:
  - Physical disabilities.
  - Intellectual disabilities.

Getting Help Paying for Medications

Medications can be expensive. To help with costs, you can ask your child's medical team about:

- Prescribing generic versions of name-brand medications.
- Using medications that work just as well but cost less.

Here are a few programs and resources that you may also find helpful.

Prescription drug discount card programs

These programs can be used at pharmacies nationwide and allow people to access lower prices on prescription medications. There is no cost to sign up for these programs. Examples include:

America's Pharmacy
Website: www.americaspharmacy.com
Phone: 888-495-3181

BeMedWise
Website: www.bemedwise.org
Phone: 978-281-6666

Choice Drug Card
Website: https://choicedrugcard.com
Phone: 800-232-7598

GoodRx
Website: www.goodrx.com/discount-card
Phone: 855-268-2822

SingleCare
Website: www.singlecare.com/prescription-discount-card#fw
Phone: 844-234-3057

ScriptSave WellRx
Website: www.wellrx.com
Phone: 800-407-8156

Community organizations

Some community organizations offer help finding access to or covering the cost of medications. Examples include:

NeedyMeds
Website: www.needymeds.org
Phone: 800-503-6897

Rx Outreach
Website: www.rxoutreach.org
Phone: 888-796-1234

Setting Up and Obtaining Medical Equipment

The type of medical equipment needed for care of your child at home may range from therapy balls and walking aids (like canes and walkers) to automatic pill dispensers and adaptive beds. The good news is that there are programs that can help you find the right equipment for your child, and some may help you learn to use it and set it up. Examples include:

Durable Medical Equipment (DME) loan closet

A DME loan closet, also known as a medical equipment lending or reuse program, is a community-based service where individuals can borrow basic medical equipment for free or for a small fee. To find a DME in your area, visit: https://gotdme.org/search/.

State assistive technology (AT) programs

State AT programs also offer a range of services for people living with disabilities, including device demonstrations, lending libraries, training, and technical assistance. They can help with ramps, as well as help you find programs that can assist with home modifications. Find your state AT program: https://at3center.net/state-at-programs/.

Medication Tracker

Pharmacy phone number:___________________

Name of Medication	Reason Taken	Dose and Directions	Prescribing Provider	Side Effects	Notes

What to Do If Your Child Gets a Brain Injury at Work

Report and get documentation of the injury

If your child is injured at work, it is important to notify their employer immediately. This is required in most states to qualify for workers' compensation. You or your child should also request a copy of the documentation of the injury in writing, including information from any witnesses to the injury. In some states, delays of 10 days or more can eliminate benefits and access to ongoing treatment.

Organize and keep records

Create a folder for:

- Medical reports and bills
- Work communications
- Workers' compensation claims forms
- Travel expenses for medical care
- Any notes about your child's symptoms and recovery

Learn about state laws on Workers' Compensation Rights

Each state has its own workers' compensation laws. Visit your state's labor or workers' compensation website or contact an attorney specializing in workplace injury for guidance. Under many state laws, your child may get costs covered for:

- Medical care
- Lost wages
- Ongoing treatment or therapy

Consider getting legal help

You may consider speaking to a workers' compensation or personal injury lawyer if:

- The claim is denied
- Benefits are delayed or cut off
- The injury leads to long-term symptoms or disability
- There is pressure from the employer to return to work too soon

It is important to get legal advice from an attorney who understands brain injury and workers' compensation laws when filing a workers compensation claim. The disability rating is determined by an independent medical examiner (IME) who evaluates a person's maximum medical improvement (MMI).

Many states have Workers Compensation Board offices where you can get more information about current laws and practices. To find an attorney with the appropriate expertise to assist you, contact the National Brain Injury Information Center at 1-800-444-6443 or visit www.biausa.org/preferredattorneys.

Legal and Financial Considerations

Advance directive

An advance directive is a written statement of a person's wishes about future medical care, including what end-of-life measures should or should not be taken depending on what the person wants to have happen. An advance directive guides decisions when a person cannot think clearly, cannot understand things or cannot tell people what health care is desired, and can be temporary in nature. The most common types of advance directives are living wills, health care proxies, and powers of attorney. Most states have created instructions and forms to help people create advance directives. The state attorney general's office is often the best resource for information on state-specific forms and procedures, and major medical institutions also may make these forms publicly available on their websites. Also, the hospital ombudsman can be an independent source of knowledge and even act as a witness to these forms.

Advocate

An advocate is an individual or agency chosen to serve the best interests of a person with a brain injury. Advocates can help deal with legal or ethical issues and may pursue funding or services on behalf of the injured person. Every person disabled by a brain injury has the right to seek the assistance of an advocate. Legal representation and advocacy services may be obtained from protection and advocacy agencies. Such agencies guard against abuse and neglect, advocate for the basic rights of individuals in institutions, and oversee governmental agencies that provide housing, treatment, and education. For more information, contact the National Disability Rights Network at www.ndrn.org.

Client rights

Client rights are a guarantee, expressed in writing, of the basic rights of people in treatment programs. Staff members must adhere to these rights in their facilities. A violation of these rights could be considered unlawful and serve as grounds for a lawsuit. Client rights include:

- Personal rights (i.e., the right to be treated with dignity and respect and to live in a safe and clean environment).
- Treatment rights (i.e., the right to receive prompt and adequate treatment in the least restrictive manner).
- Communication and privacy rights (i.e., the right to have visitors, to use the telephone, and to have privacy).
- Medical record privacy rights.

Competency or capacity

Only a court can rule whether or not a person is able to make informed choices about things like finances, health care, and where to live. The judge's ruling concerning an individual's competence is based on evidence presented during a hearing. When a judge determines a person is unable to make informed choices, the individual is deemed "incompetent" or "incapacitated." Children are automatically deemed incompetent due to their age until they reach adulthood or are emancipated by a court.

Durable power of attorney

A durable power of attorney is a legal document that gives the power to make important legal, financial, and/or health care decisions for another person (known as a personal representative or agent) when the person is unable to do so. In contrast to a power of attorney, a durable power of attorney remains in effect when a person becomes incapacitated and unable to make decisions. Just as with the power of attorney, the document must specifically say what decisions the person is allowed to make.

Durable power of attorney for health care only

A durable power of attorney for health care is a legal document that gives the power to make health care decisions only (not legal, financial, or other decisions) to another person (often known as a health care proxy or attorney-in-fact for health care) and to ensure that health care providers give the type of care the person wishes to receive. It may include specific instructions about the person's wishes about the use of life-sustaining treatments, such as feeding tubes, breathing machines, and intravenous fluids.

Guardianship

A guardian is a person (or persons) appointed by a court to make decisions on behalf of a person who cannot make decisions for themselves. Depending on the type of guardianship, the guardian may make personal (including medical and living arrangement) decisions. A parent is usually considered the guardian of a child unless court action has resulted in the appointment of a legal guardian. The process for having a guardian appointed by a court and types of legal guardianship vary by state.

Conservatorship

A conservator is a person (or persons) appointed by a court to make legal and financial decisions on behalf of a person who cannot make decisions for themselves. A parent is usually considered the conservator of a child unless court action has resulted in the appointment of a conservator. A person can be appointed as both a guardian and conservator.

Supported Decision-Making

Supported Decision-Making is a way for a person living with a brain injury to make their own choices with help from people they trust. Instead of someone else making decisions for them, the person gets support to understand information, think about options, and communicate what they want. Supporters might be family members, friends, or professionals who help explain things, talk through pros and cons, or help share decisions with others like medical professionals or teachers. The goal is to help the person stay in control of their life while getting the support they need to make informed choices.

Health care proxy

A health care proxy is a document that designates a person (usually with an alternate) to make health care decisions if the person is unable to do so.

Living will

A living will is a statement, made in advance, of an individual's terminal injury or illness providing end-of-life medical instructions in the event of incapacity. Instructions in a living will guide doctors and significant others about a person's preference for life-prolonging procedures, such as allowing the use of tubes for nutrition and hydration or administering pain medicine. A living will does not give anyone the power to make health care decisions for another person and is often subject to interpretation because the instructions are usually general and must be applied to a specific situation.

Personal injury case

In the aftermath of a brain injury, individuals may need to seek the advice of an attorney. Medical treatment and long-term care services are expensive and may span many years. Individuals and families must address and make decisions on financial issues, estate planning, returning to work or school, establishing guardianship or power of attorney, and other issues. BIAA provides an interactive directory of Preferred Attorneys with experience handling brain injury cases. The directory is available at www.biausa.org/preferredattorneys, and users may search for a local attorney specializing in one of three practice areas: personal injury, civil rights, and financial issues.

Representative payee

A representative payee, or substitute payee, is a person who acts as the receiver of Social Security Disability or Supplemental Security Income for a person who is unable to manage his or her own benefits.

Special needs trust

A special needs trust can be set up for an individual who has sustained a brain injury to allow the person to receive government benefits while still receiving funds placed in trust. Funds for the trust may come from an inheritance, a lawsuit, or insurance settlement. When the beneficiary of the trust dies, any assets in the trust are used to reimburse the government for the cost of his or her medical care. If the trust is funded by donations from unrelated people, this "payback" provision does not apply. Legal advice is needed to set up a special needs trust.

ABLE (Achieving Better Life Experience) accounts

ABLE accounts are tax-free savings that can be used to cover qualified disability-related expenses, including medical care, education, housing, and transportation. Visit www.ABLEnrc.org to learn more.

Visit **www.biausa.org/preferredattorneys** to find a lawyer who understands brain injury and is qualified to assist you and your child.

Insurance Overview

You may feel like a detective trying to find and understand health and other insurance policies to help your child access benefits. If you find that there is a lack of coverage, you may need help paying for medical, rehabilitation, community and long-term care and other services.

Depending on your child's unique situation, one or more federal, state or private options may be available to help. The best way to find out if your child is eligible for programs or benefits is to apply as soon as possible after an injury. If eligibility is denied, be sure you understand why. Sometimes, updating the application or appealing the decision will be successful.

Individual plans

Health insurance policies generally cover basic medical care, prescription medication, vision, and dental services. There is a lot of variability among health plans regarding what costs are covered. It is very important to get a copy of your child's insurance policy and to understand its limits and rules.

Sometimes staff at the hospital or rehabilitation facility can help provide insight into your policy as well as advice on getting coverage for your child. Getting help from someone who understands how health insurance companies work can make the process easier.

The costs for your child's care may include:

- **Deductibles:** The dollar amount you must pay before the insurance carrier pays for most services.
- **Copayments:** Fees paid when receiving a specific service (e.g., $10 for a primary care physician office visit).
- **Coinsurance:** The percent of the bill you will have to pay after having met the policy deductible. In an 80/20 split, for instance, the carrier pays 80 percent of the cost, while the insured is responsible for the remaining 20 percent.

Most policies also include an out-of-pocket maximum, after which the insurance carrier will pay 100 percent of the cost of the services covered. These deductibles, copays, coinsurance, and out-of-pocket maximums are generally lower when medical professionals and facilities are in the insurance company's network. When your child's medical professionals or the facility they are in are out of network, coverage by the insurance company is often denied completely. Some health insurance policies are health maintenance organizations (HMOs). This means a person must stay in-network for the insurance company to pay for services—unless it is for emergency care. Preferred provider organizations (PPOs) are another type of policy. PPOs offer more out-of-network options but usually have a higher monthly cost. Some PPO plans require referrals and/or prior authorization for certain services.

Employer plans

If your child is or was covered under an employer health plan at the time of their injury, contact The employer's Human Resource Department or Employee Assistance Program to obtain a copy of the policy (not just a summary of benefits). If you are unable to return to work after the injury, look into COBRA insurance eligibility. While it may be difficult to afford this health coverage, it may be critical to maximizing treatment and recovery. Assistance may be available for COBRA payments that can extend the protection of health coverage for many months after the employer stops paying the premium. Also, check to see if your child is covered under any of your employer's disability insurance or other employer benefits.

Long-term care insurance

Some insurance companies offer long-term care policies privately. A long-term care insurance policy can help pay for the care needed at home or in an assisted living facility or nursing home. Long-term care insurance might also pay expenses for day care, care coordination, and other services. Some long-term care policies will reimburse home modification costs. Most policies have a 100-day waiting period before benefits begin and require that the individual need assistance with at least two activities of daily living. A co-payment may be required.

Financial support for caregivers

Some programs, including some state Medicaid programs and insurance providers, pay family or friends of people with disabilities to help with daily activities. This can include personal care, giving medicine, cooking, and cleaning. Visit **www.usa.gov/disability-caregiver** and **https://careforth.com/how-we-help/** to learn more about programs and options for caregivers.

State Brain Injury Association Affiliates and Chapters

The Brain Injury Association (BIA) in your state will be a valuable resource for information about programs, resources, support groups, services, and more. Contact information for state BIA affiliates and chapters is listed on the following two pages. If you do not see your state listed, email braininjuryinfo@biausa.org for information about brain injury programs and resources in your state.

BIA of Arizona
Website: www.biaaz.org
Phone: 888-500-9165

BIA of Arkansas
Website: www.biaarkansas.org
Phone: 501-747-9596
Email: arkansasbia@gmail.com

BIAA – California Chapter
Website: www.biausa.org/california
Phone: 800-444-6443
Email: braininjuryinfo@biausa.org

BIA of Colorado
Website: www.biacolorado.org
Phone: 303-355-9969

BIAA – Delaware Chapter
Website: www.biausa.org/delaware
Phone: 302-346-2083
Email: braininjuryinfo@biausa.org

Brain Injury Florida
Website: www.braininjuryfl.org
Phone: 800-444-6443

BIA of Georgia
Website: www.braininjurygeorgia.org
Phone: 404-712-5504
Email: info@braininjurygeorgia.org

BIA of Hawaii
Website: www.biausa.org/hawaii
Phone: 800-444-6443
Email: braininjuryinfo@biausa.org

BIA of Idaho
Website: www.biaid.org
Phone: 208-385-3013
Email: info@biaid.org

BIA of Illinois
Website: www.biail.org
Phone: 312-726-5699
Email: info@biail.org

BIA of Indiana
Website: www.biaindiana.org
Phone: 317-410-3532
Email: biassociationofindiana@gmail.com

BIA of Iowa
Website: www.biaia.org
Phone: 855-444-6443

BIA of Kansas and Greater Kansas City
Website: www.biaks.org
Phone: 913-754-8883
Email: info@biaks.org

BIAA – Kentucky Chapter
Website: www.biausa.org/kentucky
Phone: 800-444-6443
Email: braininjuryinfo@biausa.org

BIA of Louisiana
Website: www.biala.org
Phone: 504-982-0685
Email: info@biala.org

BIAA – Maine Chapter
Website: www.biausa.org/maine
Phone: 800-444-6443
Email: biamaine@biausa.org

BIA of Maryland
Website: www.biamd.org
Phone: 410-448-2924
Email: info@biamd.org

BRAIN INJURY ASSOCIATION OF AMERICA

For more information on brain injury organizations and support in your state, please visit **www.biausa.org/find-bia.**

BIA of Massachusetts
Website: www.biama.org
Phone: 508-475-0032
Email: biama@biama.org

BIA of Michigan
Website: www.biami.org
Phone: 810-229-5880
Email: info@biami.org

BIA of Mississippi
Website: www.msbraininjury.org
Phone: 601-981-1021
Email: info@msbraininjury.org

BIA of Missouri
Website: www.biamo.org
Phone: 314-426-4024
Email: info@biamo.org

BIA of Nebraska
Website: www.biane.org
Phone: 402-423-2463
Email: info@biane.org

BIA of New Hampshire
Website: www.bianh.org
Phone: 603-225-8400
Email: mail@bianh.org

BIA of New York State
Website: www.bianys.org
Phone: 518-459-7911
Email: info@bianys.org

BIA of North Carolina
Website: www.bianc.net
Phone: 919-833-9634
Email: bianc@bianc.net

BIA of Ohio
Website: www.biaoh.org
Phone: 833-783-1495
Email: help@biaoh.org

BIA of Oklahoma
Website: www.biaok.org
Phone: 918-789-0406
Email: braininjuryoklahoma@gmail.com

BIA of Pennsylvania
Website: www.biapa.org
Phone: 800-444-6443
Email: birl@biapa.org

BIA of Puerto Rico
Website: www.thelsgfoundation.org
Phone: 800-444-6443
Email: fundacionlsg@gmail.com

BIA of Rhode Island
Website: www.biari.org
Phone: 401-228 3319
Email: braininjurycenter@biari.org

BIA of South Carolina
Website: www.biaofsc.com
Phone: 877-TBI-FACT
Email: director@biaofsc.com

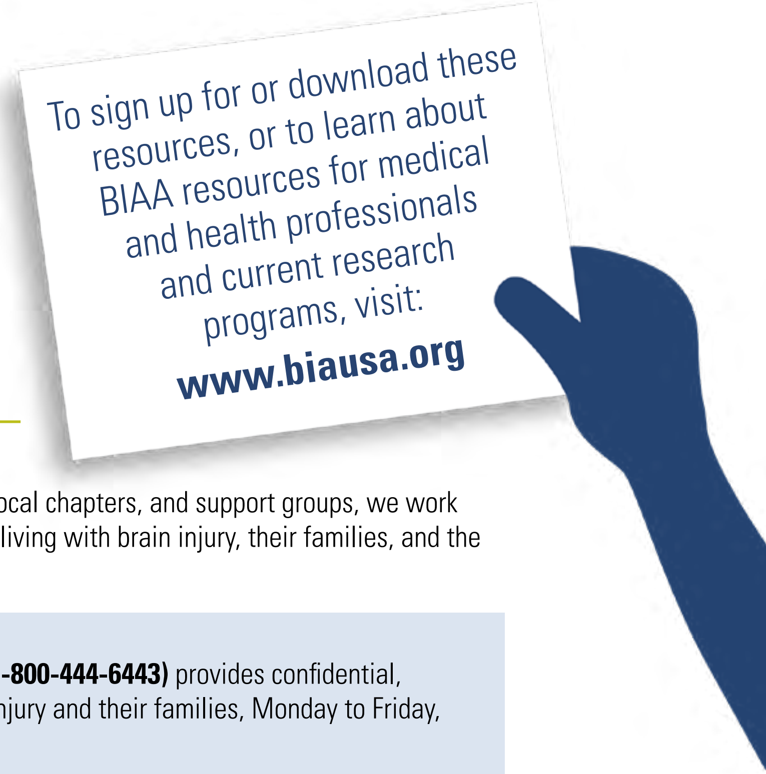
BIAA – Tennessee Chapter
Website: www.biausa.org/tennessee
Phone: 615-988-9638
Email: braininjuryinfo@biausa.org

BIAA – Texas Chapter
Website: www.biausa.org/texas
Phone: 737-497-3566
Email: braininjuryinfo@biausa.org

BIA of Virginia
Website: www.biav.net
Phone: 804-355-5748
Email: info@biav.net

BIA of Wisconsin
Website: www.biaw.org
Phone: 262-790-9660

Get to know the Brain Injury Association of America



To sign up for or download these resources, or to learn about BIAA resources for medical and health professionals and current research programs, visit:

www.biausa.org

With a nationwide network of chartered state affiliates, local chapters, and support groups, we work to bring help, hope, and healing to millions of individuals living with brain injury, their families, and the professionals who serve them.

- **The National Brain Injury Information Center (1-800-444-6443)** provides confidential, personalized assistance to people living with brain injury and their families, Monday to Friday, 9 a.m. to 5 p.m. ET.
- **The My Brain Injury Journey Campaign** was created to help people living with brain injury and their families share their stories and help inspire and learn from others.
- **Brain Injury Fundamentals** is a training and certificate program for anyone interested in learning about the unique needs and challenges of caring for a person living with brain injury.
- **THE Challenge!** magazine is the brain injury community's go-to resource for news about living with brain injury, public policy, research, medical advances, legal and financial issues, and inspiring stories of recovery.
- **Carolyn Rocchio Caregiver webinars** provide practical strategies for families on managing issues related to caring for a family member living with a brain injury. Carolyn Rocchio webinars are available free of charge for caregivers.
- **Butch Alterman Survivor webinars** is a free webinar series for people living with brain injury that aims to help people navigate life after brain injury.
- **News + Resources** is a monthly newsletter that highlights emerging research and key topics that affect people living with brain injury and families.
- **The Advocate's Update** is a quarterly newsletter that provides the latest news on brain injury-related laws and policies that may affect the brain injury community.
- **Follow BIAA on YouTube, Facebook, Instagram, or LinkedIn** to get updates, learn about activities and events, and connect with others in the brain injury community.

About this guide

We understand that the brain injury journey involves not just survivors, but also their family and friends. For this reason, this guide was lovingly put together by medical professionals, families, and survivors of brain injury. It was created for people caring for a child who was hospitalized for a brain injury or who has been experiencing the effects of brain injury. We encourage you to take your time while reading this guide and to take notes along the way. We've included key takeaways for each section, as well as handouts and checklists that you can use on your journey.

What to pack for your brain injury journey:*

- ☐ **Phone number for BIAA's National Brain Injury Information Center (1-800-444-6443)**
- ☐ Patience during setbacks
- ☐ Time for yourself to recharge
- ☐ Resilience and hope
- ☐ A sense of humor to help relieve stress
- ☐ Love and help from others
- ☐ Companionship with animals
- ☐ Grocery and meal delivery services
- ☐ A positive outlook

*This list was created with input from real caregivers and people living with brain injury. The needs of each family will vary.

BRAIN INJURY ASSOCIATION
OF AMERICA

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