



Understanding Pediatric Brain Injury – A Guide for Parents and Teachers



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Introduction

A brain injury can affect every area of a child's life, including thinking, behavior, emotions, communication, physical abilities and personal relationships. Recovery from a brain injury is a process that takes time and can be difficult. Ongoing lifestyle and relationship adjustments may be necessary. Family activities, schedules, roles and responsibilities often must change. Educators may need to make changes to help the child function in school.

This guide is intended to help family members, teachers and other caregivers understand common thinking, behavioral, emotional and communication changes that can result from a child's brain injury. It also outlines strategies to help a child adapt to these changes, and issues that may arise when the child returns home, to school and to the community. After reading this information, discuss questions or concerns with a member of your child's health care team.

Note: In this guide, "brain injury" refers to acquired brain injury, which occurs after birth and changes the brain's function.

The Team Approach to Brain Injury

Many people play a role during your child's recovery after a brain injury. Your child's health care team is an important source of information and support. The team can recommend a treatment plan and help you learn skills to meet your child's needs. Health care team members may include:

- Your child's **primary care physician**.
- **Physiatrists** — Physicians who specialize in physical medicine and rehabilitation, including pediatric brain injury rehabilitation.
- **Rehabilitation nurses** — Nurses with training and expertise in children's brain injury rehabilitation and discharge planning.
- **Neuropsychologists** — Professionals with training and expertise in evaluating and treating thinking, behavioral and emotional changes caused by a brain injury.
- **Physical therapists** — Professionals who evaluate and treat changes in your child's physical abilities.
- **Occupational therapists** — Professionals who evaluate and treat thinking and perception problems your child may have acquired, and help your child maintain or learn independent living skills (for example, swallowing, eating, dressing, managing money and safety awareness).
- **Speech therapists** — Professionals who evaluate and treat communication and thinking problems your child may have acquired.
- **Recreation therapists** — Professionals who help your child explore and participate in leisure activities.
- **Clinical nurse specialists** — Professional nurses who can provide information about brain injury and help you work with your child's school system.
- **Social workers** — Professionals who provide information and emotional support, and help with discharge planning and management of financial and other resources.
- **Other professionals**, such as chaplains, dietitians, child life specialists (professionals who specialize in children's growth and development) and vocational (employment) counselors.

You and your child are important members of the health care team. Active participation in treatment and rehabilitation is essential to recovery. The involvement of other family members, caregivers, friends and school personnel also can help your child successfully return home and to the community.

Brain Structure and Function

The effects of a brain injury depend partly on the injury's location. Understanding the brain's structure and function is helpful. The brain has two halves (cerebral hemispheres). Each hemisphere has four parts (lobes) (Figure 1). The brain's parts work together to control movement, feelings, thoughts and behavior, as described below:

- **Occipital lobes** — Located in the back of the brain, the occipital lobes receive and process visual information.
- **Parietal lobes** — Located in front of the occipital lobes, the parietal lobes process information from the sense of touch, from body position in space and from body awareness.
- **Temporal lobes** — Located on the sides of the brain, the temporal lobes specialize in memory and hearing. The dominant temporal lobe (usually on the left side) is important in speech and language.
- **Frontal lobes** — Located inside the front of the skull, the frontal lobes are the largest lobes. They control voluntary movement (movement you think about and do), such as getting out of a chair. They also are responsible for organizing information, solving problems, attention span, regulating emotion and behaviors, self-awareness, memory, language and communication.

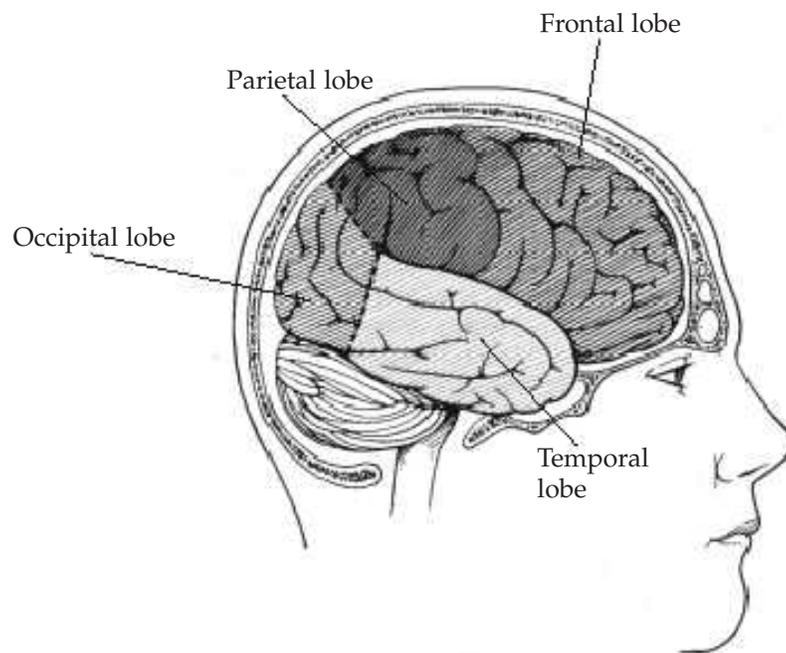


Figure 1. Structural areas of the brain

Each half (hemisphere) of the brain has distinct functions (Figure 2). The *left hemisphere* controls:

- Language and speech.
- Thinking and memory involving words.
- Moving the right side of the body.

The *right hemisphere* controls:

- Recognizing and understanding visual patterns or designs.
- Expressing and understanding emotion.
- Nonverbal communication.
- Moving the left side of the body.

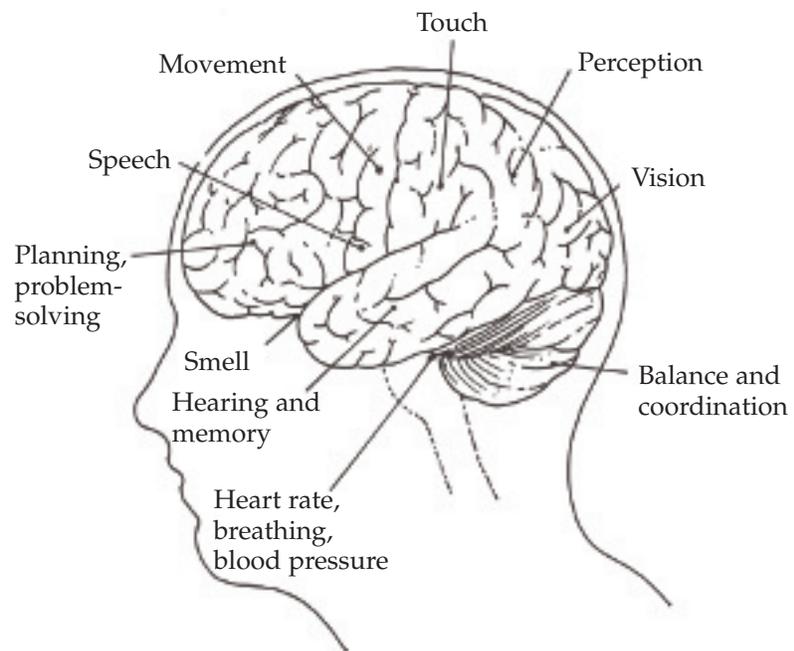


Figure 2. Functional areas of the brain

Causes of Brain Injury

Brain injury's causes include:

- **Aneurysm** — Ballooning of a weakened wall of a vein, artery or the heart.
- **Anoxia** — Lack of oxygen to the body and brain tissue, which damages the cells.
- **Concussion** — A temporary disturbance of brain function resulting from a fall or blow that jars the brain within the skull, also called mild traumatic brain injury.
- **Contusion** — An injury on the brain's surface, similar to a bruise.
- **Diffuse axonal injury** — An injury caused by pulling, stretching or tearing of cells throughout the brain.
- **Edema** — Swelling caused by more-than-normal fluid in brain tissue. With pressure buildup, edema also can result in brain cell damage and blood flow interruption.
- **Encephalitis** — A potentially life-threatening infection or inflammation of the brain.
- **Hematoma** — Pooled blood inside the brain tissue or on the surface of the brain. With pressure buildup, hematomas also can result in brain cell damage and blood flow interruption.
- **Hemorrhage** — Profuse bleeding (internal or external) caused by damage to a blood vessel.
- **Meningitis** — An infection and inflammation of the central nervous system that affects the membranes and cerebrospinal fluid surrounding the brain and spinal cord.
- **Skull fracture** — Breaking the skull (bone that covers the brain).
- **Stroke** — An interruption of blood flow to part of the brain, caused by an artery blockage, hemorrhage or aneurysm. Decreased blood flow results in little or no oxygen delivery to brain cells.
- **Traumatic brain injury** — Any injury to the brain that results from a violent force (trauma) to the head, such as an injury from a motor vehicle accident, fall or physical blow.
- **Tumor** — An abnormal growth, or tissue that resembles normal tissue but has no function. The tumor may be malignant (cancerous) or benign (noncancerous).

The Recovery Process

Recovery from a brain injury is a process that takes time, often months or years. However, various treatment options and coping strategies can help life gradually feel “normal” again for you and your child.

The following sections describe common stages of recovery and treatment options. This information is only a guide, since each child responds differently to a brain injury. Your child’s recovery and treatment plan will be unique.

Stages of recovery

Researchers do not understand exactly what happens to the brain during recovery after injury or why children’s brains respond differently to similar injuries. Factors such as age and the severity and location of a brain injury can affect, but do not entirely predict, the outcome of recovery. For example, some children with significant brain injuries experience only mild long-term difficulties, while others need lifelong, special care.

Nevertheless, most children with a significant brain injury progress through common recovery stages. The length and outcome of each stage cannot be predicted. During recovery, a child may shift back and forth between stages.

In the first few weeks after a brain injury, swelling, bleeding or changes in brain chemistry often affect the function of healthy brain tissue. The child’s eyes may remain closed, and he or she may show no signs of awareness.

As swelling decreases and blood flow and brain chemistry improve, brain function usually improves. With time, the child’s eyes may open and he or she may begin to have sleep-wake cycles, follow commands, respond to family members and speak.

A period of confusion and disorientation often follows, during which the child cannot learn new things and may appear agitated, nervous, restless or frustrated. Sleeping patterns may be disrupted. He or she also is likely to overreact to stimulation and perhaps become physically aggressive. During this time, family and friends can help by creating a calm, quiet environment (for example, limiting the number of people in the child’s room, turning off the television and dimming the lights).

Later stages of recovery can bring increased brain function. The child’s ability to respond gradually may improve. While the body cannot replace damaged or destroyed brain tissue, other parts of the brain may slowly learn to take over functions of the damaged tissue.

Treatment of brain injury

A broad range of therapy, testing and other treatment exists to help children after a brain injury. Depending on the nature of their injury, some children need only regular follow-up appointments with a health care provider. Others receive therapy, tests and monitoring on an outpatient basis. Still others begin treatment in an intensive care unit (ICU) or a general hospital unit, later may be transferred to a rehabilitation unit, and then, after leaving the hospital, continue therapy as an outpatient.

During the early weeks after injury, treatment focuses on stabilizing a child's physical condition, preventing complications such as pneumonia and blood clots, and addressing medical issues that arise (for example, removing blood or other fluid buildup to reduce swelling and pressure in the brain).

When the health care team determines that the child is ready, the rehabilitation process can begin. Rehabilitation encourages the body's natural healing process through:

- Stimulating and enhancing physical and thinking abilities.
- Learning new techniques to compensate for lost physical, mental and behavioral skills.

Early on, therapy strives to keep the child safe and increase awareness of his or her surroundings. For example, the health care team may need to help the child relearn date, time and location and understand what happened to him or her.

As mental and physical abilities progress, the focus shifts to improving attention span and mobility, coping with memory and thinking problems and increasing independence in self-care skills. The child may participate in stretching, strengthening and range of motion exercises. Community outings to practice skills learned in the hospital may be included.

How much and what rehabilitation therapy children receive depends on factors such as level of awareness, need for rest, and the ability to participate in therapy.

Since children's brains are still developing, some effects of a brain injury are not known until later in life. Therefore, your child should continue to be monitored for delayed impacts of a brain injury. If you have concerns about your child's thinking, behavior or emotions, even years after a brain injury, contact a member of the health care team.

Compensation Strategies

The following sections outline common thinking, behavioral, emotional and communication changes that can occur after a brain injury, and ways to help your child cope with such changes (compensation strategies). These strategies are designed to build on your child's strengths and work around (compensate for) deficits or problems that result from a brain injury.

Compensation strategies work best with a team approach among your child, family members, teachers and other caregivers. Consistent and frequent repetition of these strategies by all caregivers increases the chance of success.

Each child is unique, so a technique that works well for one child may not work for another. Try one strategy for two or three weeks. If it does not work, try another suggested strategy or develop and try your own solution. If, after trying several solutions to a problem, nothing seems to work, ask a member of your child's health care team to help you develop an approach that works for your child.

Thinking Changes After Brain Injury

A brain injury can affect your child's thinking. It can disrupt your child's alertness, concentration, attention, learning, memory, reasoning, planning and problem-solving skills. Below are common thinking problems for a child with a brain injury, what you may see and suggested ways to help.

Problem	What you might see	How to help
<p>Confusion</p>	<ul style="list-style-type: none"> • Confused about how to complete tasks or activities • Confuses past and present events • Confabulates (makes up convincing stories to fill memory gaps; this is not intentional lying) 	<ul style="list-style-type: none"> • Encourage the child to write events, tasks and schedules in a notebook or calendar.* • Encourage frequent review of information throughout the day. • Gently remind the child of correct details of past and present events. • Encourage the child to confirm information with others. • Establish a method for completing routine tasks. • Limit changes in daily routine. • If change in routine is necessary, help the child prepare by writing a plan in the notebook or calendar. • Provide clear, simple explanations of tasks, activities or necessary changes in daily routines.

*See "Appendix A: Memory and Organizational Aids," page 33.

Problem	What you might see	How to help
<p>Difficulty remembering</p>	<p>Difficulty:</p> <ul style="list-style-type: none"> • Remembering tasks, directions, names or activities from day to day (may make up realistic stories to fill memory gaps) • Remembering new information • Adapting to new surroundings • Adapting to changes • Learning to use memory and organizational aids (such as a notebook or calendar) • Completing tasks or projects 	<ul style="list-style-type: none"> • Establish a daily routine. • Encourage consistent use of memory aids such as calendars, notebooks and cue cards.* • Encourage the child, family members and school personnel to write new information in the child’s notebook or calendar. • Encourage frequent review and repetition of information throughout the day. • Break down directions or tasks into small steps and encourage the child to do one step at a time. For example, say “Please make your bed, then put away your toys,” instead of “Please clean your room.” • Limit how much information is presented at one time. • Regularly summarize information as it is being taught. • Allow the child more time to respond to your request or question than was necessary before the brain injury. • Provide information in different ways (such as showing, in addition to telling, or writing, instead of only talking about information).

*See “Appendix A: Memory and Organizational Aids,” page 35.

Problem	What you might see	How to help
<p>Attention and concentration problems</p>	<ul style="list-style-type: none"> • Short attention span (perhaps only a few minutes initially) • Easily distracted by sounds, movement and people • Difficulty focusing on or doing more than one thing at a time • Difficulty learning new information • Increased errors or need for repetition • May appear bored 	<ul style="list-style-type: none"> • Focus on one task at a time. • Get the child’s attention before discussion or activity begins. • Decrease distractions (turn off TV and music, close doors, allow only one or two visitors, allow only one person at a time to speak). • Gently refocus attention to details of the activity when the child is distracted. • Minimize abrupt changes. • Talk the child through changes in activities. • Ask the child to repeat information to ensure the child understood the conversation (for example, ask “Can you remind me what we are working on today?”). • Schedule brief rest periods between short work or activity periods (for example, 20 to 30 minutes of activity, five-minute break, 20 to 30 minutes of activity, etc.). Gradually increase the length of work or activity periods. • Start with familiar and enjoyable activities within the child’s attention span. Gradually increase time spent on a task.

Problem	What you might see	How to help
<p>Attention and concentration problems (continued)</p>		<ul style="list-style-type: none"> • Offer time limits. For example, say, “Let’s do this for 15 minutes and then take a break.” • Identify and minimize distractions. • Take a break or change activities if the child becomes frustrated. • Look for signs of fatigue, which can impair attention span and concentration. • Praise improvement when attention to activity lengthens.
<p>Difficulty making decisions or solving problems</p>	<ul style="list-style-type: none"> • Hesitation or inability to make decisions or solve problems • Inappropriate decisions • Impulsive reactions to situations (acting before thinking) • Difficulty reasoning • Concrete or inflexible thinking — getting stuck on one decision or solution • Anxiety, especially with new situations or problems • Inability to recognize that a problem exists, but cannot identify the problem or a solution 	<ul style="list-style-type: none"> • Help identify the problem. • Brainstorm for one or two possible solutions. Encourage the child to write optional solutions in a notebook. • Discuss the advantages and disadvantages of various options. Ask, “What might happen if you choose to do or say this?” • Try not to label solutions as right or wrong. • Set realistic expectations for the child’s age and ability level. • Role-play situations and practice responses.

Problem	What you might see	How to help
Difficulty making decisions or solving problems <i>(continued)</i>		<ul style="list-style-type: none"> • Allow learning from mistakes, unless it is unsafe. • Encourage use of the problem-solving process.* Work through problems together — do not always solve them yourself or make the child solve them alone.
Difficulty initiating activity	<ul style="list-style-type: none"> • Difficulty beginning activities or tasks • Appearing disinterested or unmotivated 	<ul style="list-style-type: none"> • Establish a daily routine. • Provide specific choices. For example, ask, “Would you like to do A or B?” rather than “What would you like to do?” • Break down tasks into simple steps and encourage the child to do one step at a time. • Set deadlines for completion of tasks. • Encourage use of the calendar or notebook. • Praise the child when he or she gets started without help or uses coping strategies. • Be patient and remember that initiation problems are common after brain injury and do not indicate lack of motivation or desire.

*See “Appendix B: Problem Solving Worksheet,” page 37.

Problem	What you might see	How to help
<p>Difficulty completing a task</p>	<ul style="list-style-type: none"> • Difficulty planning a sequence of tasks • Lack of follow-through with planned tasks • Appearing disorganized 	<ul style="list-style-type: none"> • Begin with small, realistic tasks or projects. • Explain tasks clearly and simply before the start. • Allow the child to help plan the process and help him or her write the necessary steps. • Have the child repeat or read the steps. • Encourage the child to refer to the plan and check off steps as they are completed. • Repeat and explain the sequence of activities as needed. • Allow extra time for the child to complete tasks. • Watch for signs of frustration or inattentiveness and, if necessary, stop the activity. • Give brief feedback during and at the end of a task.

Behavioral Changes After A Brain Injury

A brain injury can affect your child's behavior, including self-control, self-awareness and response to social situations. Below are common behavioral problems for a child with a brain injury, what you may see and suggested ways to help.

Problem	What you might see	How to help
Difficulty with self-control; impulsiveness	<ul style="list-style-type: none"> • Acts or speaks impulsively, with poor judgment or without considering the consequences (for example, stands up in the middle of a seated conversation, or leaves the classroom during a lecture). • Makes inappropriate comments (for example, makes rude or sexually-oriented comments) • Gets stuck on one idea or activity (perseveration) 	<ul style="list-style-type: none"> • Encourage the child to "stop and think" before acting or responding. • Limit the child's options. • Suggest alternative behavior or change the subject or activity. • Set realistic expectations for the child's age and ability level. • Provide verbal and nonverbal feedback, supportively and reassuringly. • If undesired behavior occurs, discuss the consequences privately, calmly and confidently. Avoid long, detailed explanations. • Praise and reward desired behavior immediately. • Be aware of stress and environmental, academic and social demands that may affect the child's behavior. • Model calm behavior; practice anger control.

Problem	What you might see	How to help
Impaired self-awareness	<ul style="list-style-type: none"> • The child is unaware of limitations or changes in thinking, emotions and behavior • Inaccurate self-image or self-perception 	<ul style="list-style-type: none"> • Anticipate lack of insight. • Avoid confronting or challenging the child directly. • Allow the child to try activities that involve minimal risk but help him or her realistically view current strengths and limitations (for example, trying a full day of school to learn whether he or she is ready to return full time). • Praise first, then give simple, constructive feedback about behavior. • Give feedback with specific suggestions for improvement. • Be patient. Remember that self-awareness usually improves with time.
Difficulty with social situations	<ul style="list-style-type: none"> • Acts or speaks impulsively or without considering the consequences • Difficulty taking turns • Socially inappropriate behavior or comments • Disrespectful of social boundaries 	<ul style="list-style-type: none"> • Provide clear expectations for desirable behavior. • Have realistic expectations for the child's age and present ability. • Plan and rehearse social interactions. Remind the child that actual interactions may not go as rehearsed.

Problem	What you might see	How to help
<p>Difficulty with social situations <i>(continued)</i></p>		<ul style="list-style-type: none"> • Encourage the child to slow down and think through responses. • Encourage the child to consider the consequence of his or her behavior. • Provide positive feedback for appropriate behavior. • Encourage breaks during an activity to help avoid frustration. • Respond immediately to inappropriate ideas but maintain the original focus of the discussion. For example, say “We’re not going to talk about _____. Tell me more about _____.” • If undesired behavior occurs, suggest alternative or desirable behavior, or change the activity. • Discuss the consequences of undesired behavior privately, calmly and confidently. Explain that the behavior, not the child, is inappropriate. • Encourage the child to rely on judgments of trusted adults regarding appropriate behavior.

Emotional Changes After A Brain Injury

A brain injury can affect the areas of the brain that control emotions. Below are common emotional problems for a child with a brain injury and suggested ways to help.

What you might see	How to help
<ul style="list-style-type: none"> • Difficulty controlling emotions • Mood swings ranging from anxious to sad to angry • Unpredictable emotional reactions (for example, inappropriate laughing or crying) • Reduced tolerance for frustration 	<ul style="list-style-type: none"> • Expect the unexpected. • Remain calm and reassuring when emotional outbursts occur. Allow the child to express feelings safely. • Take the child to a quiet room or area to calm down and regain control. • Provide feedback gently and supportively after the child regains control. • Avoid comparing past reactions to the present situation. • Avoid criticism or judgment. • Gently redirect the child to a different topic or activity. • Use humor positively and supportively. • Recognize that the child may use negative comments or refusal as a means of control. • Understand that brain injury often prevents the child from feeling guilt or empathy. • Pay attention to your emotional reactions to the child. • Anticipate and avoid situations that trigger troubling emotions.

Depression

Feelings of sadness, frustration and loss are common after a brain injury. Such feelings often appear during the later stages of recovery, when confusion decreases and self-awareness improves. However, if these feelings become overwhelming or interfere with recovery, the child may be suffering from depression.

Depression can arise as the child struggles to adjust to temporary or lasting disability caused by a brain injury. Depression also may occur if the injury has affected areas of the brain that control emotions.

Being depressed is not a sign of weakness, nor is it anyone's fault. Depression is a physical illness, like high blood pressure or diabetes. A child cannot get over depression by simply wishing it away, using more willpower or "toughening up." Fortunately, most children who have depression can be helped with medication and other therapies.

Following are symptoms of depression:

- Persistent sadness
- Irritability, moodiness
- Anxiety
- Loss of interest or pleasure in life
- Neglect of personal responsibilities or personal care
- Changes in eating habits or sleeping patterns
- Fatigue, loss of energy, lack of motivation
- Extreme mood changes
- Feeling helpless, worthless or hopeless
- Physical symptoms (for example, headaches or chronic pain) that do not improve
- Withdrawal from others
- Thoughts of death or suicide

If your child has symptoms of depression, talk with his or her health care provider. Effective treatments are available, including individual and group therapy, medication or a combination. Early treatment can help prevent needless suffering.

If your child expresses suicidal thoughts or threatens to harm himself or herself, immediately call 911 or your local emergency services provider.

Communication Changes After A Brain Injury

A brain injury can affect a child's speech and language abilities. Through language, a child receives and expresses ideas. Language is linked to cognition (thinking ability) and involves listening, understanding, reading and writing. Language also involves speaking, understanding and conversing.

A brain injury can affect the muscles necessary for speech. Communication problems also may arise if the injury impairs behavior and thinking skills, reduces attention and ability to focus, leads to difficulty remembering, reasoning or solving problems, or produces lack of self-awareness. Below are common communication problems for a child with a brain injury, what you may see and suggested ways to help.

Problem	What you might see	How to help
Difficulty starting conversation	<ul style="list-style-type: none"> • Does not start or is slow to start conversations, ask questions or make comments • Does not respond to another person's questions or comments • Long pauses between comments 	<ul style="list-style-type: none"> • Encourage speaking by asking open-ended questions, such as, "What do you think about _____?" or "Tell me about _____." • Give the child your full attention. • Give the child time to organize his or her thoughts and respond. • Restate what the child has said, for example ask, "Do you mean _____?"
Difficulty following conversation	<ul style="list-style-type: none"> • Difficulty paying attention to what is said • Does not understand or misinterprets what is said • Difficulty grasping the main idea of a conversation 	<ul style="list-style-type: none"> • Get the child's attention before speaking. • Ask the child to look at you when you speak. • Ask the child to repeat what you said. • Speak slowly, clearly and simply. • Pause between statements to allow processing time.

Problem	What you might see	How to help
Difficulty following conversation <i>(continued)</i>		<ul style="list-style-type: none"> • Reduce distractions or move to a quiet area. • Explain the main idea of the conversation. • Offer to repeat what was said. • Encourage the child to ask questions if he or she does not understand.
Difficulty taking turns in conversation	<ul style="list-style-type: none"> • Talks too much; does not give the listener a turn to speak. • Talks too little; does not participate in conversations. 	<ul style="list-style-type: none"> • Politely interrupt and ask the child for a chance to speak. • Ask the child to, "Please make it brief," or say that you would like to speak. • If the child talks too much, encourage him or her to listen more often or to stop and think before speaking. • If the child talks too little, ask for his or her viewpoint or for more details; ask open-ended questions.
Difficulty dealing with topics	<ul style="list-style-type: none"> • Difficulty selecting topics for conversation • Difficulty keeping up when topics change • Introduces a new topic abruptly or drifts from one topic to another without transition • Difficulty giving a detailed explanation or description 	<ul style="list-style-type: none"> • Ask about his or her interests and opinions. • Clarify new topics as they arise. • Ask how the child's comment relates to the topic. Say, "Do you mean _____?" • Tell the child you are confused or "getting lost" in the conversation. Say, "Let's get back to talking about _____."

Problem	What you might see	How to help
Difficulty dealing with topics <i>(continued)</i>	<ul style="list-style-type: none"> • Difficulty finding the right words • Using words or expressions incorrectly 	
Speaking unclearly	<ul style="list-style-type: none"> • Slurred speech • Speaks too loudly or softly • Speaks too rapidly • Speaks in a monotone voice or without emotion 	<ul style="list-style-type: none"> • Tell the child you did not understand and ask him or her to repeat and speak slowly. • Establish and use consistent gestures or cues (for example, cup your hand to your ear as a reminder to speak louder). • State that you are unsure what he or she is saying. • Ask directly, for example, "Can you tell me the point you are trying to make?" • Suggest practicing strategies learned in speech therapy, such as speaking slowly, using short sentences or checking to see if the listener understands.

Problem	What you might see	How to help
<p>Nonverbal communication problems</p>	<ul style="list-style-type: none"> • Does not seem to understand or react to common nonverbal cues, such as facial expressions, head nodding or tone of voice • Stands too close or too far from the listener • Makes an uncomfortable number or type of physical contacts • Body language or facial expressions do not seem to match what the child says • Distracting, repetitive or excessive body movements • Poor eye contact or staring at others during conversation 	<ul style="list-style-type: none"> • Ask the child to maintain a comfortable distance. • Ask the child to change the type of physical contact he or she makes; explain that his or her behavior makes you feel uncomfortable. • Say that the difference between the child's body language and spoken message confuses you. • Ask the child what he or she is feeling. • Ask the child to stop his or her distracting movements. • Show how changing facial expressions and other body movements, such as head nodding, are important to communication.

Other Effects of A Brain Injury

A brain injury can affect physical abilities (such as balance, mobility, coordination and muscle strength, tone and control) and the body's senses (hearing, vision, smell, touch and taste). A brain injury also can cause fatigue and produce conditions such as seizures and spasticity.

Fatigue

Fatigue is common during brain injury recovery. Fatigue may result from the injury itself (and other injuries in cases of trauma) or from additional physical and mental effort required to do tasks that once were performed with little or no effort. Fatigue can make physical functioning, attention and concentration, memory and communication difficult.

When a child with a brain injury first returns home, it can be difficult to know how much he or she can or should do. Often during this transition, the child and family members become discouraged with the slow pace of recovery and changes in responsibilities. Remember that this is just one step in the recovery process. In time, the child's stamina and energy level likely will improve, and his or her activities may be increased.

Trying to do too much too soon can lead to frustration. You can help by encouraging your child to:

- Resume activities gradually, over days, weeks or even months.
- Work on tasks slowly and steadily.
- Set a schedule that includes regular rest breaks or naps. Gradually decrease the length and number of breaks as the child recovers.
- If the health care team recommends, use assistive aids (for example, a cane for walking) to conserve energy.

Seizures

An acquired brain injury sometimes causes seizures. A sudden, excessive, disorderly electrical discharge of brain cell activity produces a seizure. The risk of developing seizures is related to the severity and type of brain injury. The risk seems to be greatest in the first two years after injury, then declines gradually.

The two types of seizures that can occur after brain injury are generalized (grand mal) and partial. Most seizures last only a few minutes. Generalized seizures involve involuntary jerking or shaking of most or all four limbs, unresponsiveness and loss of bladder control. The person may cry out, stiffen and fall, become flushed or turn blue and have difficulty breathing. Partial seizures may involve loss of awareness, staring, unusual verbal responses, lip smacking or other repetitive motions, or involuntary jerking or shaking of one body part without loss of consciousness. A partial seizure may progress to become generalized.

If your child has a seizure, try to remain calm and take these steps:

1. Make sure the child is in a safe area and put something soft under his or her head if the child has fallen.
2. Loosen tight clothing, such as a belt, and remove eyeglasses.
3. Clear the area of anything that could harm the child.
4. Place the child on his or her side, keeping the chin away from the chest. This position allows saliva to drain from the mouth and helps the airway remain open.
5. Do not force your fingers or any object into the child's mouth.
6. **Do not restrain the child. You cannot stop the seizure.**

Dial 911 or your local emergency services number if:

- This is the child's first seizure.
- Breathing does not resume after a seizure and mouth-to-mouth resuscitation is necessary.
- Recovery after a seizure is not complete and another seizure begins.
- The child is injured during a seizure.
- A seizure continues for more than five minutes.
- The child has an existing seizure disorder and a situation arises where you have been told to seek emergency medical treatment.

The possibility that a child with an acquired brain injury could experience seizures is frightening. Fortunately, the chances are not high and the child's medical team can usually prescribe medications to effectively manage a seizure disorder. Until a seizure-free interval has been maintained (often 6 to 12 months), driving privileges may be restricted by law (see "Driving restrictions," page 29, and "Activity restrictions," page 30).

Spasticity

Injury to the part of the brain that controls movement can cause spasticity, an abnormal increase in muscle tone. (Tone is the amount of tension or resistance to movement in a muscle.) Unlike a normal muscle, a spastic muscle that is stretched does not easily relax. Instead, the muscle remains stiff or may not move at all.

Spasticity usually is not immediately present after a brain injury, but may develop gradually over weeks or months. Spasticity symptoms range from slight to severe muscle stiffness. Spasticity can impair the ability to dress, eat, write, balance, move and walk.

Managing spasticity may be lifelong. Treatment varies depending on the child's age, the severity of symptoms and related conditions or complications. Your child's health care provider can give you more information.

Returning Home After A Brain Injury

Recovery from brain injury continues after your child leaves the hospital. The following sections discuss issues your child may face while adjusting to life at home, school and in the community.

Relationship issues

Family roles and relationships often change after a child has a brain injury. Family members may feel confused, angry, afraid, guilty, frustrated or helpless because of changes in how the child thinks, talks and behaves. Parents may have to resume roles they had when the child was younger. For instance, a teen who was previously quite independent and responsible may now need more supervision and assistance. Siblings may not know how to act around a child with a brain injury. They also may feel neglected by parents and jealous of the attention the child receives.

Addressing family relationship issues early is important. Open communication can help family members identify stresses and explore possible solutions to problems. Encourage all family members to express their feelings without placing guilt or blame. Talking with a friend or member of the health care team also may be helpful.

A brain injury can affect a child's relationships with friends and peers. Changes in the child's behavior, physical appearance and mood, and in thinking, communication and social skills can make resuming established friendships difficult. Other children may feel awkward or fearful around a child with a brain injury. Taking time to explain a brain injury and its effects to friends and peers can help them feel more comfortable and better able to interact with the child.

Romantic relationships are an important aspect of adolescence. From childhood on, we are taught how to express love and affection. A brain injury may alter the ability to appropriately express such feelings. A teenager with a brain injury may not understand when it is appropriate to touch, hug or kiss other people or may not be able to make responsible choices about sexual activity.

Parental guidance and support are especially important to help the teen learn how to express affection and love appropriately. Responsible sexual behavior and birth control options should be discussed openly. Although talking about love and sexuality can be difficult, discussing these concerns is an essential part of reducing the risk of physical and emotional harm to the teen with a brain injury. Members of the health care team are resources to help you address these issues.

Returning to school

For children and teens, returning to school is important for social and educational growth. At school, young people find friends and peer support, develop social skills and increase their knowledge. School also provides a place to monitor children's intellectual and social development. Sometimes, the effects of a brain injury are not obvious in young children, but become apparent later as the thinking and social demands of school increase. Various standardized tests and activities (neuropsychological evaluations) can help assess a child's thinking and emotional functioning, track his or her progress over time, and plan educational and vocational programs.

Most children with a brain injury return to school. A gradual return often is recommended to help make the transition as successful as possible. Specific recommendations for your child will depend on the effects of his or her injury and the resources available in your local school system.

Federal and state laws mandate special programs and accommodations that school systems must make to help children with brain injuries return to school. Most schools have staff trained as special educators, although not all special educators are familiar with the needs of children with a brain injury. If a specialist is not available through your child's school system, ask your child's health care team members to consult with school personnel and help them develop an education plan for your child.

Common special accommodations that may help a child with brain injury to learn in school include:

- Extra time for tests to compensate for slower thinking or information-processing abilities
- Taking tests privately in a distraction-free environment to accommodate for difficulties with attention, concentration and increased distractibility
- Verbal rather than written tests
- Placement in classrooms with less noise and fewer distractions
- Tape recording lectures to compensate for attention, concentration and memory problems
- Access to teachers' or peers' class notes to compensate for memory and concentration problems or difficulty taking notes while listening to a lecture
- Tutoring with a peer or a professional
- Shortened school day or modified class schedule to compensate for fatigue and concentration problems
- Identifying a place to rest or take breaks during the day

Parents and family members often must be advocates for the child, to assure adequate services are available for a successful return to school. Parents and family members also may need to serve as active links between the rehabilitation professionals and the school personnel responsible for developing the child's education plan. In some states, a brain injury educational consultant is available through the office of special education. This consultant can help educators in local schools assess and arrange services for students with brain injuries. Your child's health care team also can provide information about resources available through the school system and state government.

Leisure time

A child with a brain injury may have more unstructured time than before the injury. This can be particularly true before the child can return to school full time. The brain injury also may affect the child's interest and ability to participate in some activities. Your child must have healthy ways to spend leisure time.

Leisure activities aid children's growth and development. Physical activity (for example, sports, dancing, biking or walking) promotes physical and mental health. Pursuits such as craft projects, drawing, writing or playing an instrument allow a child to express emotions and creativity. Social activities (for example, playing or talking with friends, going to a movie or participating in a musical group) provide friendship and contact with others.

If your child has trouble choosing leisure activities, talk with a recreation therapist or another member of the health care team. These professionals can suggest ways to help your child return to previous activities and develop new interests.

Driving restrictions

If a person with a brain injury has seizures or physical, thinking or vision impairments that make driving unsafe, state or local laws may prohibit driving for a time. Some states require that physicians notify a state office if it is unsafe for a person to drive. Other states rely on physicians to help people with brain injuries make wise decisions about driving. State laws also vary on requirements for reinstating a restricted driver's license. Talk with the health care team to be sure you understand driving restrictions.

Activity restrictions

For your child's safety, the health care team may recommend activity restrictions. Avoiding additional brain injury is especially important. To help keep your child safe:

- Be sure your child uses a seat belt or age- and weight-appropriate car seat when riding in a motor vehicle.
- Follow activity restrictions specified by your child's health care provider. The health care provider may recommend that your child not participate for a time in contact sports (such as football, hockey or wrestling) or other activities that put him or her at risk for another brain injury (such as snowmobiling, using power equipment, jumping on a trampoline or riding a bicycle or horse). When to return to such activities depends on the health care provider's recommendations and on factors such as your child's balance, strength, reaction time and judgment.
- If your child returns to contact sports or similar activities, be sure he or she wears a helmet designed specifically for the activity.

Use of alcohol and drugs

Rehabilitation professionals strongly recommend that a child with a brain injury abstain from alcohol and tobacco products and take only medications the child's physician recommends. Drinking alcohol, using street drugs or substances, or taking prescribed medication incorrectly can worsen the effects of a brain injury. Alcohol and drug use can interfere with thought processes, seriously damage brain cells and nerves, and disturb:

- Alertness and concentration.
- Self-awareness.
- Perception.
- Memory and learning.
- Reasoning, planning and problem solving.
- Speech and language.
- Motor control, balance and coordination.
- Emotions.
- Decision making.
- Self-control.

Although changing someone's drug or alcohol habits can be hard, family members and others close to the child can be motivators to discourage alcohol and drug use.

To provide support:

- Take substance abuse seriously and avoid thinking of it as being temporary.
- Help the child create a plan to cope with situations that have led to past alcohol or drug use.
- Rehearse ways to avoid or react differently to such situations.

A rehabilitation psychologist or chemical dependency specialist can help assess whether your child has a drug or alcohol problem. Chemical abuse programs can help a child or adolescent with a brain injury recover from substance abuse. Talk with a member of your child's health care team if you have questions or concerns.

Role Changes and Support for the Caregiver

A family member's brain injury affects the whole family. The usual family roles, routines and responsibilities may be interrupted or changed. One significant change is that someone becomes a caregiver.

A caregiver is anyone who takes primary care of someone else, either permanently or temporarily. Providing companionship, emotional support and physical care for the child with a brain injury may be necessary. Caregivers also may have many other responsibilities, including employment outside the home, and caring for the home and other children. Being a caregiver can be overwhelming, and adapting to these changes is challenging.

Take a few minutes to identify how the roles in your family have changed. What new responsibilities have you added to your daily routine? How have the changes affected your life?

As a caregiver, you must take care of yourself, so that you have something to give others. The following suggestions may help:

- **Ask for help when you need it.** Caregivers often try to do everything alone. Expecting too much of yourself may increase your stress. Do not be afraid to ask other family members, friends and neighbors for help. Home health care or respite care may be available in your community to provide care when you cannot.
- **Set limits.** The hours in the day are limited. Maintain a healthy pace. Some tasks and activities may need to be postponed.
- **Plan something to look forward to each day.** Reward yourself for caring.
- **Take a break from the child relying on your care.** Taking an hour, a day, a weekend or a week away can help restore your emotional well-being.
- **Maintain your support system.** You need family and friends with whom you can discuss concerns and have fun.
- **Maintain your health.** Caregivers are vulnerable to stress-related illnesses. If you have questions or concerns about your health, make an appointment and tell your health care provider that you are under unusual stress.
- **Take time for exercise.** Exercise increases stamina, lessens anxiety and depression, improves or maintains muscle tone and strength, and increases self-confidence. These benefits make exercise a worthwhile use of your limited time.
- **Learn relaxation techniques.** These can be as simple as deep-breathing exercises or more complex, such as biofeedback.
- **Join a support group.** Support groups provide an opportunity to share problems and concerns. People with similar life circumstances can understand your concerns.
- **Keep your sense of humor.** Laughter can help reduce stress.

Additional Resources

Mayo Clinic is closely linked to the Rochester community and the region. Mayo Clinic also is affiliated with a growing network of regional care facilities — Mayo Health System. Mayo Health System practices are located in 58 other communities in southern Minnesota, western Wisconsin and northern Iowa. Members of your child's health care team can help you find appropriate local facilities if follow-up care is necessary at home.

Talk with members of your child's health care team about resources that can provide additional information and assistance. The Brain Injury Association of America (BIA) is an important resource for people with brain injuries. This national, nonprofit organization is dedicated to brain injury prevention, research, education and advocacy. Most states have BIA affiliates, which operate programs and services that connect brain injury survivors, their families and friends, health care professionals and communities. The BIA can be found on the Internet through your favorite search engine or through the Internet addresses listed below:

www.mayoclinic.com
www.healthfinder.gov
www.medlineplus.gov

Contacting Your Child's Health Care Provider

If you have questions about your child's condition, acquired brain injury or this information, call Mayo Clinic and ask for your child's health care provider.

Mayo Clinic Rochester, Minn.
507-284-2511

Appendix A: Memory and Organizational Aids

Memory and organizational aids can provide greater independence for a child with a brain injury.

Calendar

A calendar (or notebook) can help a child plan and organize daily activities, step by step. It also can be used to record events, plan ahead, review successes, check off completed tasks and serve as a reminder of tasks to be completed. Below is a sample calendar page to help you get started.

Wednesday FEBRUARY 26		Wednesday FEBRUARY 26	
Things To Do		Time	Description
✓ Make bed		8	8:30 - Catch school bus #2
Pick up toys		9	
Put away clothes			
Do homework		10	10:30 - Miss Jones, Room 110 Speech class
Practice speech exercises		11	
		12	
		1	
		2	
		3	Ride school bus #2 home
		4	Play at Jimmy's house
		5	

Notes:

Cue cards

Cue cards, such as the sample below, can remind a child with a brain injury how to manage more effectively.

Compensation cue card

Compensation techniques

- Stop and think
- Slow down
- Take one step at a time
- Read and follow directions
- Take notes and refer to them
- Ask questions
- Do not assume
- Pay attention to details
- Use the problem-solving process
- Think about the consequences of not finishing a task

Appendix B: Problem-Solving Worksheet

1. Define the problem. _____
2. Come up with possible solutions.
3. Compare the advantages and disadvantages of each possible solution.

Possible solutions	Advantages	Disadvantages

4. Pick a solution to try.
5. Evaluate the success of the solution.
6. Try another solution if the first one is not working.

Notes

Notes

Notes



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