

PATIENT EDUCATION

*Understanding Brain Injury*  
A Guide for the Family

learning **EDUCATION** EXCELLENCE  
HEALTHY **LIVING** CARING INTERACTION

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# Table of Contents

<b>Introduction</b> .....	3
<b>A Team Approach</b> .....	5
<b>Brain Structure and Function</b> .....	7
<b>Causes of Brain Injury</b> .....	9
<b>The Recovery Process</b> .....	11
Stages of recovery .....	12
Treatment of brain injury .....	13
<b>Compensation Strategies</b> .....	15
<b>Thinking Changes After a Brain Injury</b> .....	16
<b>Perceptual changes</b> .....	20
<b>Behavioral Changes</b> .....	23
<b>Emotional Changes</b> .....	26
Depression .....	27
Self-esteem .....	29
<b>Communication Changes</b> .....	30
<b>Other Physical Effects of Brain Injury</b> .....	33
Fatigue .....	33
Seizures .....	34
Spasticity .....	36
Swallowing .....	37
Bladder and bowel .....	38
<b>Life After Brain Injury</b> .....	40
Going home .....	40
Relationships .....	40
Sexuality .....	42
Driving .....	43
Returning to work .....	43
Returning to school .....	44
Recreation and leisure .....	45
Use of alcohol and drugs .....	46
Activity restrictions .....	47

<b>Available Resources .....</b>	<b>48</b>
<b>Contacting Health Care Providers.....</b>	<b>50</b>
<b>Appendix A: A Partnership Approach .....</b>	<b>51</b>
<b>Appendix B: Memory and Organizational Aids .....</b>	<b>52</b>
Calendar .....	52
Cue Cards.....	54
<b>Appendix C: Problem-Solving Worksheet .....</b>	<b>55</b>
<b>Appendix D: Americans with Disabilities Act.....</b>	<b>56</b>
<b>Summary.....</b>	<b>57</b>

# Introduction

## Key Messages

- Brain injury affects virtually every area of a person's life.
- The relationships, roles and responsibilities of family members and other people close to the person will experience a period of adjustment.
- Adjustments are best made in small steps with the instruction and guidance of health care team members.

Brain injury is a life-altering event which affects every area of a person's life — including his or her relationship with family members and others close to him or her. The phrase *acquired brain injury* refers to medical conditions that occur to the brain (usually after childhood), changing its function. These conditions include stroke, traumatic brain injury, tumor and other diseases of the brain.

The effects of brain injury often change roles and responsibilities within the family. Family members and others close to a person with brain injury may struggle to cope with behavioral changes caused by the brain injury. The injured person also may struggle to adjust. Family members and others close to the person may feel stressed, burdened, even depressed by the major changes in activities, responsibilities, daily schedules, leisure and support that are required to adjust to the consequences of acquired brain injury.

Often, major adjustments are best made in small steps. Simple changes may help the person with brain injury, family and friends to find more enjoyment in their relationships and activities. By taking each stressful situation one step at a time, the person with brain injury and family may feel that life is becoming a little more "normal" again.

This booklet contains information on the human brain, causes of acquired brain injury, the recovery process, and behavior, communication and physical changes after brain injury. It also outlines examples of stressful behaviors and situations that people with brain injury may experience. Possible solutions follow each example. A solution that works well for one person may not work for another. For this reason, the best way to use this booklet is to try one solution for two or three weeks. If that solution does not work, try another.

Sometimes, the ideas in this booklet stimulate families to develop unique solutions to challenges. If, after trying several solutions to a problem, nothing seems to work, seeking advice from a professional may help. A brain injury psychologist (neuropsychologist), clinical social worker or other behavior specialist can help analyze and develop an approach that considers the special features of the patient's situation.

Recovery from brain injury is a process that takes time. In recent years, brain rehabilitation as a specialty has advanced in its understanding of ways to encourage and maximize recovery. Your team will use all available knowledge and techniques while caring for your loved one. Consult any member of the health care team to address your concerns and questions.

# A Team Approach

## Key messages

- Many people play a role in a person's recovery after a brain injury.
- You and your loved one with brain injury are the most important members of the health care team.

The health care team is an important source of information and support to the injured person and family. The team can recommend a treatment plan and help you learn skills to meet specific needs. Health care team members may include:

- **A primary care physician.**
- **Physiatrists** — Physicians who specialize in physical medicine and rehabilitation, including brain injury rehabilitation.
- **Rehabilitation nurses** — Nurses with training and expertise in 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 physical abilities.
- **Occupational therapists** — Professionals who evaluate and treat thinking and perception problems, and help an injured person maintain or learn independent living skills (for example, swallowing, eating, dressing, managing money and safety awareness).
- **Speech language pathologists or speech therapists** — Professionals who evaluate and treat communication and thinking problems.
- **Recreation therapists** — Professionals who help a person with brain injury explore and participate in leisure activities.
- **Clinical nurse specialists** — Professional nurses who help coordinate care of patients with brain injury and support and educate their families about the injury and recovery process.

- **Social workers** — Professionals in the hospital and outpatient settings who help guide the adjustment to acquired brain injury. They provide information on discharge planning, assessment of financial resources, and community resource referrals. They may also assist in addressing stress management and the development of effective coping and adjustment strategies.
- **Other professionals**, such as respiratory therapists, child life therapists, chaplains, dietitians, and vocational (employment) counselors.

You and the person with brain injury 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 co-workers also can help the person with brain injury successfully return home and to the community.



# Brain Structure and Function

The human brain has billions of nerve cells. They are arranged in patterns that work together to control thought, emotion, behavior, movement and sensation. For reference, it helps to know about the brain's structure and function.

The brain is divided into two halves that look nearly the same but differ in many functions. The halves are called the **cerebral hemispheres** (figure 1). These are further divided to create four separate areas called **lobes**.

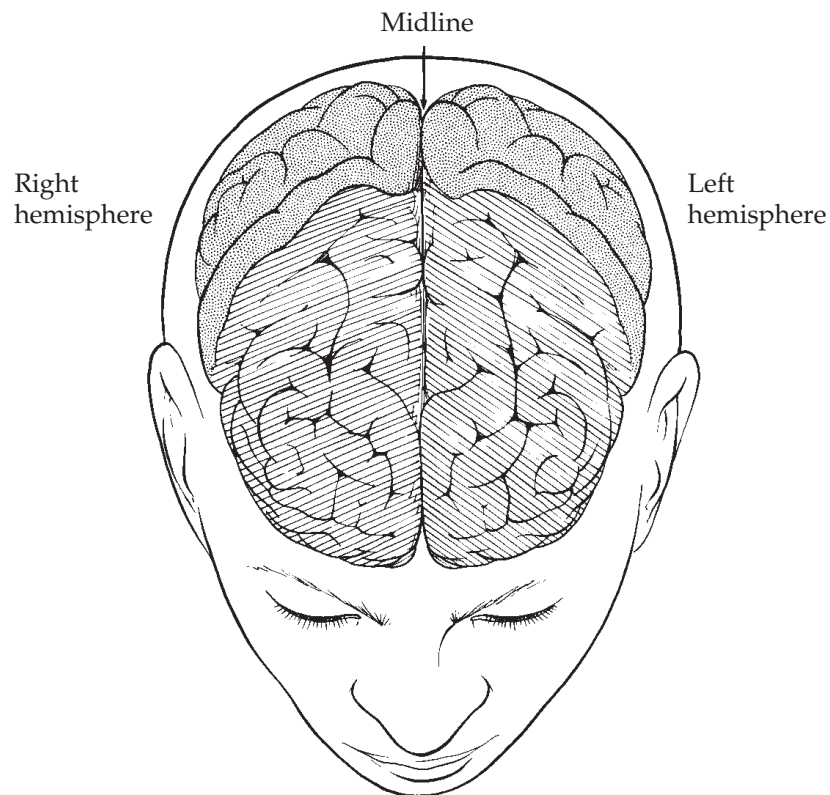


Figure 1. Cerebral hemispheres

For most people, the left half of the brain controls verbal functions including language, thought and memory involving words. The right half controls nonverbal functions. These include, for example, recognizing the differences in visual patterns and designs, reading maps and enjoying music. The right hemisphere also is involved in expressing and understanding emotions.

Although each half of the brain has distinct functions, the two parts actually work closely together to control the activity of the body. The left side of the brain controls movement and sensation in the right side of the body, and the right side of the brain controls movement and sensation in the left side. Thus, damage to the right side of the brain may cause movement problems or weakness on the body's left side.

Specific parts of the brain control specific functions. The effect of a brain injury is partially determined by the location of the injury (figure 2).

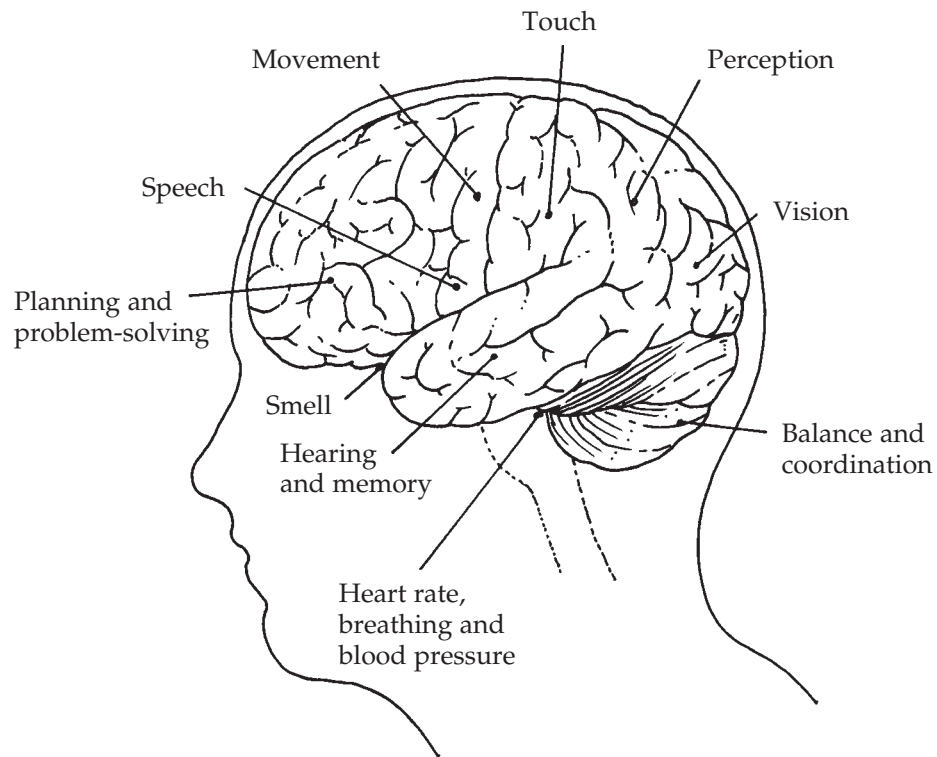


Figure 2

# *Causes of Brain Injury*

Causes of brain injury may include:

**Acquired brain injury** — Refers to medical conditions that occur to the brain (usually following birth), changing its function. These conditions include stroke, traumatic brain injury, brain hemorrhage, tumor, anoxia and other non-degenerative diseases of the brain.

**Aneurysm** — Ballooning of a weakened wall of a vein, artery or the heart.

**Anoxia** — Lack of oxygen to 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 its surface. 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.

**Mild traumatic brain injury** — A temporary disturbance of brain function resulting from a fall or blow that jars the brain within the skull.

**Skull fracture** — A break in 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 reaching 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 looks normal, but has no function. The tumor may be malignant (cancerous) or benign (noncancerous).

# Recovery Process

## Key messages

- Recovery from a brain injury is a process that takes time.
- Various treatment options and coping strategies can help life gradually feel “normal” again.

Recovery following a brain injury may be measured in weeks, months or years, and slows with the passage of time. Some of the effects of brain injury can be long-lasting and recovery may be incomplete. Although some people with severe brain injuries experience only mild long-term difficulties, others may require care or special services for the rest of their lives.

In the days and weeks immediately following brain injury, the function of surviving brain tissue is often affected by swelling, bleeding and/or changes in the brain’s complex chemistry. Sometimes blood accumulation must be removed surgically to reduce swelling and pressure within the brain. Controlling swelling and allowing time for the brain’s blood flow and chemical systems to recover usually lead to improved function.

Exactly what happens in the brain during the later stages of recovery is not clear, but some parts in the process are becoming clearer. New research is shedding light on brain tissue and its capacity to repair itself. Many things can occur that help restore surviving brain tissue to maximize function. For example, although the total number of brain cells may not change, it is thought that surviving brain tissue has the capacity gradually to learn how to perform some functions of destroyed cells.

In cases of traumatic brain injury, trauma often occurs to other parts of the body, with associated bleeding, swelling and changes in function. The effects of these other injuries can prolong overall recovery and maybe even further damage the brain. For instance, excessive bleeding may deprive the brain of needed blood and oxygen. Prompt treatment of associated injuries may help limit brain damage.

The medical community is gradually realizing how a damaged brain recovers. Current treatment methods are based on a growing understanding of the brain’s recovery processes.

## Stages of recovery

### Key messages

- Most adults with a brain injury progress through common recovery stages.
- The length and outcome of each stage cannot be predicted.
- During recovery, a person may shift back and forth between stages.
- Inconsistency is common.

Researchers do not understand exactly what happens to the brain during recovery. 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 people with significant brain injuries experience only mild long-term difficulties, while others need lifelong, special care.

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 injured person's eyes may remain closed, and the person may not show signs of awareness.

As swelling decreases and blood flow and brain chemistry improve, brain function usually improves. With time, the person's eyes may open, sleep-wake cycles may begin, and the injured person may follow commands, respond to family members, and speak.

A period of confusion and disorientation often follows, during which the person's ability to pay attention and learn stops and agitation, nervousness, restlessness or frustration may appear. Sleeping patterns may be disrupted. Overreaction to stimulation and physical aggression may result. This stage can be disturbing for family because the person behaves so uncharacteristically.

Inconsistent behavior also is common. Some days are better than others. For example, a person may begin to follow a command (lift your leg, squeeze my finger) and then not demonstrate this behavior again for a time. This stage of recovery may last days or even weeks for some. However, once demonstrated, a behavior usually appears again. In this stage of recovery, try not to become anxious about inconsistent signs of progress. Ups and downs are normal.

Family and friends can help by creating a calm, quiet environment (for example, limiting the number of people in the person's room, turning off the television and dimming the lights). In addition, ask questions of the clinical nurse specialist and others on the health care team, who are responsible for keeping you accurately informed. You are encouraged to ask questions to stay abreast of your loved one's progress.

Later stages of recovery can bring increased brain function. The person's ability to respond may improve gradually. New research is investigating the body's ability to replace damaged brain tissue. Other parts of the brain, however, may slowly learn to assume functions of the damaged tissue.

### **Treatment of brain injury**

#### **Key messages**

- A broad range of therapy, testing and other treatment options are available to help people after a brain injury.
- Treatment for brain injury is tailored to meet individual needs.
- Members of the health care team determine when the rehabilitation process will begin.

Depending on the nature of the brain injury, some people 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, and may be transferred later to a rehabilitation unit. After they leave the hospital, therapy as an outpatient may continue.

During the early weeks after injury, treatment focuses on stabilizing the person'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 person with brain injury is ready, the rehabilitation process can begin. Rehabilitation encourages the body's natural healing process through:

- Stimulating and enhancing physical and thinking abilities.
- Teaching new techniques to compensate for lost physical, thinking (cognitive) and behavioral skills.

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

As cognitive 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 person may participate in stretching, strengthening, balance and range of motion exercises. Community outings to practice skills learned in the hospital may be included.

How much and what rehabilitation therapy the person with brain injury receives depends on factors such as level of awareness, other injuries such as fractures, the need for rest, and the ability to participate in therapy.

If you have concerns about your loved one's thinking, behavior or emotions, even years after a brain injury, contact a member of the brain rehabilitation 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 the person with brain injury cope with such changes (compensation strategies). These strategies build on the person's strengths and work around (compensate for) deficits or problems that result from a brain injury.

Compensation strategies work best with a team approach that includes the person with brain injury, family members and other caregivers. Consistent and frequent repetition of these strategies by all caregivers increases the chance of success.

Each person is unique, so a technique that works well for one person 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 the health care team to help you develop a different approach.

**\*See Appendix A: "A Partnership Approach"**

# Thinking Changes After Brain Injury\*

Brain injury can disturb:

- Alertness and concentration
- Self-awareness
- Perception
- Memory and learning
- Reasoning, planning and problem-solving
- Speech and language
- Motor control
- Emotions

The information that follows will help familiarize you with behavior, memory and thinking problems that a person with brain injury may experience. Also included are techniques to help the person participate more effectively and comfortably in the family. Consistent and frequent repetition of these techniques listed will increase the chance of success.

Do not hesitate to contact any member of the brain rehabilitation team if you have questions or need assistance and suggestions.

Problem	Signs	What to do
<p><b>Confusion</b></p>	<ul style="list-style-type: none"> <li>• Confuses times/ tasks in schedule of activities</li> <li>• Confuses past and present events</li> <li>• Confabulates (makes up convincing stories to fill memory gaps; this is not intentional lying)</li> </ul>	<ul style="list-style-type: none"> <li>• Encourage the use of a notebook to log events and encourage the person to refer to it for details of daily events.</li> <li>• Gently remind the person of correct details of past and present events.</li> <li>• Confirm accurate information with other people.</li> <li>• Arrange for consistency in routine tasks (use calendar and notebook).</li> <li>• Limit changes in daily routine.</li> <li>• Provide clear, concise explanations of even the most basic changes in daily routines.</li> </ul>

<b>Problem</b>	<b>Signs</b>	<b>What to do</b>
<b>Difficulty remembering</b>	<ul style="list-style-type: none"> <li>• Unable to remember tasks from day to day</li> <li>• Unable to remember new information</li> </ul>	<ul style="list-style-type: none"> <li>• Establish a structured routine of daily tasks.</li> <li>• Encourage the consistent use of memory aids such as calendars and notebooks to plan, record and check off tasks as completed.</li> <li>• Encourage the person to write new information in the memory notebook.</li> <li>• Encourage other family members also to write any information they need to communicate to the person.</li> <li>• Encourage review and rehearsal of this information frequently throughout the day.</li> <li>• Provide opportunities for repeated practice of new information.</li> <li>• Try to pair new information with facts the person can recall.</li> <li>• Provide spoken cues as needed for recall and, if necessary, help fill in memory gaps.</li> </ul>
<b>Attention problems</b>	<ul style="list-style-type: none"> <li>• Limited ability to focus</li> <li>• Distractible</li> <li>• Difficulty in attending to one or more things at a time</li> </ul>	<ul style="list-style-type: none"> <li>• Focus on one task at a time.</li> <li>• Be sure you have the person's attention before beginning a discussion or task.</li> <li>• Decrease distractions when working or talking with the person. (Eliminate or reduce noises.)</li> </ul>

Problem	Signs	What to do
<b>Attention problems</b> <i>(continued)</i>		<ul style="list-style-type: none"> <li>• Praise any improvement in length of attention to activity.</li> <li>• Gently refocus the person's attention to specific details of the activity as needed.</li> <li>• Keep abrupt changes to a minimum.</li> <li>• Ask the person to repeat information that was communicated to be sure the person understood the conversation.</li> <li>• Schedule brief rest periods between short periods of work or activity (for example, 20 to 30 minutes of work, a five-minute break; 20 to 30 minutes of work, etc.).</li> </ul>
<b>Difficulty with decision making</b>	<ul style="list-style-type: none"> <li>• Hesitation with decisions</li> <li>• Inappropriate or potentially harmful decisions</li> <li>• Difficulty reasoning</li> <li>• Ineffective problem solving</li> </ul>	<ul style="list-style-type: none"> <li>• Encourage the person to "stop and think." Many people with brain injury benefit from a note or a stop sign on the front of their notebook reminding them to "stop and think."</li> <li>• Use the Problem-Solving Worksheet (Appendix C)</li> <li>• Help the person explore various options to solving problems.</li> <li>• Have the person write possible options in the notebook.</li> <li>• Discuss advantages and disadvantages of each option.</li> <li>• Role-play to prepare the person for various situations.</li> </ul>

Problem	Signs	What to do
<b>Difficulty with initiation</b>	<ul style="list-style-type: none"> <li>• Has trouble getting started</li> <li>• Appears disinterested or unmotivated (this is typically not intentional)</li> </ul>	<ul style="list-style-type: none"> <li>• Help the person develop and follow a structured daily routine.</li> <li>• Provide specific choices for daily tasks. For example, ask, “Would you like to do A or B?”</li> <li>• Simplify tasks. Break down tasks into simple steps and complete one step at a time.</li> <li>• Encourage use of the notebook or calendar to set specific deadlines for tasks to be completed.</li> <li>• Praise the individual for starting without assistance.</li> <li>• Establish a time frame for accomplishing tasks.</li> </ul>
<b>Difficulty carrying out a plan of action</b>	<ul style="list-style-type: none"> <li>• Lack of follow-through to completion with a task</li> <li>• Difficulty planning a sequence of tasks</li> <li>• Appears disorganized</li> </ul>	<ul style="list-style-type: none"> <li>• Begin with small, realistic projects.</li> <li>• Include the person in planning the activity.</li> <li>• Provide a clear explanation of an activity before starting.</li> <li>• Break down new or complex tasks into several easier steps.</li> <li>• Have the person write the a step-by-step list as a plan.</li> <li>• Ask the person to tell you these steps to ensure understanding.</li> <li>• Encourage the person to refer to the plan, and check off each task that is completed.</li> </ul>

\* See Appendix B: “Memory and Organizational Aids” and Appendix C: “Problem-Solving Worksheet”

# Perceptual Changes

Perception is the brain's ability to gather information and make sense of it. Perceptual changes may cause people with a brain injury not to realize what they feel, see or hear, even though their senses of touch, sight and hearing are fine. Perceptual changes may impair the ability to judge distance, size, position and speed of movement.

After acquiring a brain injury, the person may experience some of the following:

- Unilateral neglect (neglect of one side of the body)
- Visual field cut (each eye sees only half or a portion of its visual field)
- Apraxia (inability to use an object or do familiar tasks)
- Difficulty with spatial relations

Perceptual changes following brain injury can be temporary or permanent. The following information is intended to help identify perceptual changes and how to adapt to them.

Problem	Signs	What to do
<b>Unilateral neglect</b>	<ul style="list-style-type: none"> <li>• Bumps into objects on the affected side</li> <li>• Turns head toward the unaffected side</li> <li>• Ignores food on the side of the plate on the affected side</li> <li>• Fails to dress the affected side of the body</li> <li>• Forgets to bathe or attend to other hygiene tasks on the affected side</li> <li>• Applies makeup to only one side of the face</li> <li>• Jabs the eye on the affected side when putting on glasses</li> </ul>	<ul style="list-style-type: none"> <li>• Ask visitors to stand on the affected side to encourage the person to look toward that side.</li> <li>• Position bed and chair to encourage looking toward the affected side.</li> <li>• Position bright objects on the affected side. This "visual cueing" should be done only when the person is alert and not tired.</li> </ul>

Problem	Signs	What to do
<b>Visual field cut</b>	<ul style="list-style-type: none"> <li>• Suddenly notices objects that seem to appear or disappear</li> <li>• Bumps into objects on the affected side</li> <li>• Turns the head toward the unaffected side</li> <li>• Cannot see food on the side of the plate on the affected side</li> <li>• Loses track of the last location on a page where the person was reading or writing</li> <li>• When reading, cuts words in half and they cannot be understood</li> </ul>	<ul style="list-style-type: none"> <li>• Remind the person to look around the environment, especially on the affected side.</li> <li>• Mark “on” and “off” switches of frequently used items, such as televisions and kitchen appliances, with bright pieces of tape so the person can easily know when equipment is on or off.</li> <li>• Position bright objects or favorite things to the affected side and ask the person to turn his or her head until they spot the objects.</li> <li>• Draw a straight, brightly colored line down one side of a book or notebook as a cue indicating the edge of the page. Do this on the right side of the page if the right side is affected, and on the left side if the left side is affected.</li> </ul>
<b>Apraxia</b>	<ul style="list-style-type: none"> <li>• Uses objects incorrectly; for example, might use a toothbrush to comb hair or a fork to eat soup</li> </ul>	<ul style="list-style-type: none"> <li>• Stop the person from continuing a task the wrong way.</li> <li>• Show the person what to do by demonstrating the position or movement.</li> <li>• Place your hand over the person’s hand and move it through the correct motions to perform a task.</li> </ul>

Problem	Signs	What to do
<b>Apraxia</b> <i>(continued)</i>	<ul style="list-style-type: none"> <li>• Fails to follow spoken directions due to an inability to understand or do what is asked; for example, may not give the “thumbs-up” sign when asked</li> <li>• Puts clothes on backwards, upside down or inside out</li> </ul>	<ul style="list-style-type: none"> <li>• Redirect the person to put on clothing in correct order, one step at a time.</li> <li>• Develop a daily routine for hygiene and dressing.</li> </ul>
<b>Spatial relations</b>	<ul style="list-style-type: none"> <li>• Mistakes the location of a chair when sitting down</li> <li>• Has difficulty finding items in a cluttered room</li> <li>• Has trouble using a fork or spoon to pick up food from a plate</li> <li>• Misjudges distance; for example, misses the cup when pouring coffee</li> <li>• Misjudges space between steps when going up or down stairs</li> <li>• Reaches too far or not far enough to get objects</li> <li>• Stands too close or too far away from others in social situations</li> <li>• Requests eye appointments often, because of perception that vision is affected</li> </ul>	<ul style="list-style-type: none"> <li>• Limit clutter; keep the home and drawers organized and neat.</li> <li>• Keep items used often in the same location.</li> <li>• Provide cues with words and pictures.</li> <li>• Place brightly-colored tape across the edge of each step on stairways.</li> <li>• Remind that handrails should be used when available.</li> <li>• Encourage using both hands to feel for objects.</li> <li>• Provide gentle reminders and ask the person to move when standing too close or too far away.</li> <li>• Wait for six months after the brain injury — or the time recommended by your physician — to schedule an eye appointment. It is unlikely that the problem with perception is the result of a new problem with the eyes.</li> </ul>



# Behavioral Changes

A person with a brain injury may experience changes in behavior, including self-control, self-awareness and response to social situations. The following are common behavioral problems for a person with a brain injury, what you may see and suggested ways to help.

Problem	Signs	What to do
<p><b>Difficulty with self-control</b></p>	<ul style="list-style-type: none"> <li>• Acts or speaks without all the information or without considering the consequences</li> <li>• Impulsiveness or poor judgment</li> <li>• Lack of inhibition</li> <li>• Inappropriate comments to or about others</li> <li>• Gets stuck on one idea or activity (perseveration)</li> </ul>	<ul style="list-style-type: none"> <li>• Limit the person's choice of options.</li> <li>• Suggest alternatives for behavior.</li> <li>• Explain the reasons for tasks.</li> <li>• Be fair in your expectations.</li> <li>• Respond immediately to inappropriate ideas but maintain the original focus of the discussion.</li> <li>• Encourage the person to slow down and think through tasks or responses.</li> <li>• Provide supportive verbal and non-verbal feedback for reassurance.</li> <li>• If undesired behavior occurs, calmly and confidently discuss the consequences in private.</li> <li>• Praise and reward desired behavior.</li> </ul>

Problem	Signs	What to do
<p><b>Impaired self-awareness</b></p>	<ul style="list-style-type: none"> <li>• Lack of awareness of deficits and limitations (this is not typically intentional, but rather a common phenomenon following traumatic brain injury in particular)</li> <li>• Overestimates abilities; underestimates problems</li> <li>• Inaccurate self-image/self-perception</li> </ul>	<ul style="list-style-type: none"> <li>• Anticipate lack of insight.</li> <li>• Prompt accurate self-statements.</li> <li>• Use feedback generously and supportively.</li> <li>• Give realistic feedback as you observe behavior.</li> </ul>
<p><b>Difficulty participating in or being part of social situations</b></p>	<ul style="list-style-type: none"> <li>• Acts or speaks without all the information or without considering the consequences</li> <li>• Difficulty taking turns</li> <li>• Impulsiveness</li> <li>• Socially inappropriate behavior or comments</li> <li>• Not always sensitive to social boundaries</li> <li>• Acting out of place in unfamiliar social or public settings</li> </ul>	<p><b>What to do — before the event</b></p> <ul style="list-style-type: none"> <li>• Provide clear expectations for desirable behavior in social settings or in special circumstances such as job interviews, attending a funeral, or going to church.</li> <li>• Plan and rehearse social interactions so that they will be familiar, predictable and consistent.</li> <li>• Establish verbal and non-verbal cues to signal the person to “stop and think.”</li> </ul>

Problem	Signs	What to do
<p><b>Difficulty participating in or being part of social situations</b> <i>(continued)</i></p>		<p><b>What to do — during the event</b></p> <ul style="list-style-type: none"> <li>• Treat the person appropriately, according to age.</li> <li>• Encourage the person to slow down and think through responses.</li> <li>• Prompt the person to consider consequences of behavior.</li> <li>• Provide positive feedback for appropriate behavior.</li> <li>• Encourage a break in activity when frustration or fatigue are evident.</li> <li>• Respond immediately to inappropriate ideas but maintain the original focus of the discussion.</li> <li>• If undesired behavior occurs, calmly and confidently address the behavior in private. Be objective and explain that the behavior, not the person, is inappropriate</li> <li>• Reassure and be fair in your expectations.</li> </ul> <p><b>What to do — after the event</b></p> <ul style="list-style-type: none"> <li>• Review the behavior, the effectiveness of verbal and nonverbal uses, and the overall success of the outing.</li> <li>• Praise appropriate behavior and responses to cues and redirection.</li> </ul>

# Emotional changes

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

Problem	Signs	What to do
<p><b>Difficulty controlling emotions</b></p>	<ul style="list-style-type: none"> <li>• Mood swings ranging from anxious to sad to angry</li> <li>• Inappropriate laughing or crying</li> <li>• Lower tolerance for frustrating situations</li> </ul>	<ul style="list-style-type: none"> <li>• Expect the unexpected.</li> <li>• Remain a model of calm assurance and confidence if an emotional outburst occurs.</li> <li>• Take the person to a quiet room or area for time to calm down and regain control.</li> <li>• Provide feedback gently and supportively after the person regains control.</li> <li>• Avoid comparing past and present behaviors.</li> <li>• Gently redirect behavior to a different topic or activity.</li> <li>• Recognize that the person may use negative comments or refusal as a means of control.</li> <li>• Understand that brain injury often prevents the individual from feeling guilt or empathy.</li> <li>• Recognize your emotional reactions to the person with brain injury.</li> </ul>

Problem	Signs	What to do
<b>Intermittent distress (comes and goes)</b>	<ul style="list-style-type: none"> <li>• Unhappiness and irritability</li> <li>• Cries easily</li> <li>• Responds angrily for no apparent reason</li> </ul>	<ul style="list-style-type: none"> <li>• Acknowledge feelings.</li> <li>• Give the person a chance to talk about feelings.</li> <li>• Listen and express your desire to understand those feelings.</li> <li>• Encourage behaviors that have helped cope with stress in the past.</li> </ul>
<b>Grief</b>	<ul style="list-style-type: none"> <li>• Tearfulness</li> <li>• Restless sleep</li> <li>• A change in appetite</li> </ul>	<ul style="list-style-type: none"> <li>• Remind the person that grief is a healthy and normal response.</li> <li>• Explain that coming to terms with the loss of some abilities may take time.</li> <li>• Offer whatever support you can provide.</li> <li>• Seek guidance from a member of the health care team.</li> </ul>

### **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 person may be suffering from depression.

Depression can arise as the person 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 an illness. A person cannot get over depression by simply wishing it away, using more willpower or "toughening up." Depression after brain injury may result from biochemical and structural changes in the brain. Fortunately, medication and other therapies can help most people who have depression.

These 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 such as headaches or chronic pain that do not improve
- Withdrawal from others
- Thoughts of death or suicide

If the person with brain injury has symptoms of depression, his or her health care provider should be consulted. Effective treatments are available, including individual and group therapy, medication or a combination. Early treatment can help prevent needless suffering. Mental health professionals, including rehabilitation psychologists and social workers, are available to assist.

If your loved one expresses suicidal thoughts or threatens self-harm, immediately call 911 or your local emergency services provider.

**Self-esteem**

Self-esteem is a person's assessment of self-worth and is often adversely affected by brain injury. A problem may be more significant if the person with brain injury has had a mild to moderate injury or a severe injury with good self-awareness. The more aware the person with brain injury is, the more likely are changes in self-esteem.

**What to do:**

- Focus on the positives.
- Allow the person to express feelings.
- When necessary, redirect conversation to positive or neutral thoughts.
- Express your concern and desire to understand the person's feelings.
- Point out the person's successes, even partial successes.
- Encourage as much independence as possible.
- Do not criticize.
- Give caring, realistic feedback.
- Help the person plan ahead to maximize opportunities for success.
- Choose activities and tasks that the person can successfully complete.

Challenges vary among people with brain injury. Be aware of how you reference the person with brain injury. Avoid labeling, categorizing or stereotyping a behavior or communication skill that was altered by the injury. Learning as much as possible about brain injury and exercising patience and compassion are good steps toward understanding and nurturing the self-esteem of the person who has brain injury.

# Communication Changes

Difficulties with communication can be caused by many factors, including changes in behavior and thinking skills, problem solving, judgment, reasoning, awareness, memory loss and lack of self-awareness. Language ability and speech also may be affected by brain injury.

People with a brain injury may have changes in one or many of these areas. The severity and combination of problems vary among people.

Problem	Signs	What to do
<b>Initiating conversation</b>	<ul style="list-style-type: none"> <li>• Does not respond to another person's conversation, questions or comments</li> <li>• Does not start, or is slow to start conversations, ask questions, or make comments</li> <li>• Leaves long pauses</li> <li>• Has difficulty with explanations</li> </ul>	<ul style="list-style-type: none"> <li>• Encourage the individual to participate. For example ask, "What do you think about that?"</li> <li>• Ask open-ended questions such as, "Tell me about..."</li> <li>• Give the person time to organize thoughts. Extra time may be necessary to respond to any request or question.</li> <li>• Give the individual your full attention until the thought is completed.</li> <li>• Rephrase what he or she has said such as, "Do you mean...?"</li> </ul>
<b>Following conversation</b>	<ul style="list-style-type: none"> <li>• Has difficulty paying attention to what is said</li> <li>• Misinterprets what is said</li> </ul>	<ul style="list-style-type: none"> <li>• Get the person's attention before speaking.</li> <li>• Be clear and concise.</li> <li>• Reduce distractions.</li> <li>• Emphasize important information.</li> <li>• Offer to repeat what was said.</li> <li>• Ask the person to look at you when speaking.</li> <li>• Invite the person to ask questions or request clarification.</li> </ul>



Problem	Signs	What to do
<b>Taking turns in conversation</b>	<ul style="list-style-type: none"> <li>• Talks non-stop, does not give the listener a turn to speak</li> <li>• Does not appear to adjust communication style or behavior for the situation</li> <li>• Has a hard time selecting topics for conversation</li> <li>• Has a hard time keeping up when topics change</li> <li>• Introduces a new topic abruptly</li> <li>• Does not always stay on topic</li> </ul>	<ul style="list-style-type: none"> <li>• Politely interrupt and ask for a chance to speak.</li> <li>• Ask the person to, "Please make it brief," or announce that you would like to speak.</li> <li>• Ask about the person's interests and opinions.</li> <li>• Clarify new topics as they arise.</li> <li>• Ask how the person's comment relates to the topic, for example, "Do you mean...?"</li> <li>• Tell the person you are confused or "getting lost" in the conversation.</li> </ul>
<b>Problem with intelligibility</b>	<ul style="list-style-type: none"> <li>• Slurred speech</li> <li>• Speaks too loudly or softly, making the message hard to understand</li> <li>• Speaks too rapidly</li> </ul>	<ul style="list-style-type: none"> <li>• Tell the person you did not understand and ask to hear it again.</li> <li>• Establish and use consistent gestures or cues (for example, cup your hand to your ear as a reminder to speak louder).</li> </ul>

Problem	Signs	What to do
<p><b>Nonverbal communication</b></p>	<ul style="list-style-type: none"> <li>• Does not seem to understand common non-verbal cues</li> <li>• Stands too close or too far from conversational partner(s)</li> <li>• Uncomfortable number or type of physical contacts</li> <li>• Body language that does not seem to “match” what is said</li> <li>• Facial expressions that do not seem to “match” what is said</li> <li>• Distracting, repetitive or excessive body movements</li> <li>• Poor eye contact</li> <li>• Staring at others during conversation</li> </ul>	<ul style="list-style-type: none"> <li>• Ask the person to maintain a comfortable distance.</li> <li>• Politely ask the person to modify his or her physical contacts because you feel uncomfortable; offer an explanation if necessary.</li> <li>• Tell the person you are confused by the difference in body language and spoken message.</li> <li>• Ask what the person is feeling.</li> <li>• Politely ask the individual to stop distracting movements.</li> </ul>

# Other Physical Effects

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

## **Fatigue**

Fatigue is very common during brain injury recovery. Fatigue may result from the injury (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. Physical functioning, attention and concentration, memory and communication can be adversely affected by fatigue.

When a person with a brain injury first returns home, knowing how much that person can or should do can be difficult. Often during this transition, the person and family members become discouraged with the slow pace of recovery, changes in responsibilities, or they may try to do or expect too much. This is just one step in the recovery process. In time, the person's stamina and energy level likely will improve, and the ability to engage in activities may be increased.

The following strategies may be useful in helping the person with brain injury learn to manage fatigue:

- Encourage use of a calendar or planner to help manage mental fatigue.
- Set a schedule that includes regular rest breaks or naps. (For example, one nap in the morning and one in the afternoon after some activity, physical or mental.) Rest breaks or naps should not exceed 30 minutes.
- Avoid evening naps.
- Gradually decrease the length and number of breaks as the person's ability to tolerate activities with less fatigue improves.
- Resume activities gradually, over weeks or even months.
- Start with familiar tasks that the person can complete without fatigue.
- Gradually increase the complexity of the task, encouraging breaks as needed, to slowly increase the length of time.
- Become familiar with indicators of fatigue for the person.

*Strategies to learn to manage fatigue continued*

- Watch for signs of fatigue, such as increased inattention or distractibility, repetition of tasks or comments, irritability or increased errors.
- Encourage breaks, every five minutes, during tasks, before or as soon as signs of fatigue appear.
- If the health care team recommends, use assistive aids (for example, a cane for walking) to conserve energy or a wheelchair for long distances.
- Plan ahead for fatiguing activities, such as visitors, trips, going out.
- Schedule a nap before visitors come or before going out.
- Consider limiting the person's time with visitors or a rest break during visits.

### **Seizures**

A medical condition that may occur after brain injury is post-traumatic seizure. Seizures can be caused by a sudden, excessive, disorderly electrical discharge of brain cell activity. This risk of ongoing seizures is related to the severity and characteristics of the brain injury, such as the type and location of the brain injury. Risk seems to be greatest in the months after injury, then gradually declines with time.

Several types of seizures may occur after brain injury. The most frequent types are generalized (grand mal, tonic/clonic) and partial (partial complex and simple partial) seizures.

### **Generalized seizures**

Grand mal, tonic/clonic seizures usually involve involuntary jerking or shaking of most or all four limbs, unresponsiveness, and loss of bladder control.

Most seizures are self-limited and last only a few minutes. The person may cry out, stiffen and fall, have jerking movements, turn flushed or blue and have some difficulty breathing. Remain calm and take the following steps:

- Make sure the person is in a safe area and lay the person's head on something soft if a fall occurred.
- Loosen tight clothing such as a necktie or belt and remove eyeglasses.
- Clear away hazardous objects that may be nearby.
- Position the person lying on his or her side to keep the chin away from the chest. This will allow saliva to drain from the mouth.
- Do not force your fingers or any object into the person's mouth.
- **Do not restrain the person. You cannot stop the seizure.**

After the seizure, the person usually will be temporarily confused and drowsy. Do not offer food, drink or medication until the person is fully awake. Someone should stay with the person until fully recovered. Check for a medical identification tag on a bracelet or necklace.

Until a predetermined seizure-free interval has been maintained (often six months to one year), driving privileges are restricted by state law. During this time, extreme caution should be taken if the person will be working around heavy or dangerous equipment.

Dial 911 for emergency assistance in these situations:

- Breathing does not resume after the seizure and mouth-to-mouth resuscitation is necessary.
- Before the person recovers from the first seizure and another seizure begins.
- The person has been injured during the seizure.
- The person has awakened and requests an ambulance for emergency medical attention.
- The seizure continues for more than five minutes.

Prompt medical care is also recommended if this seizure is the person's first or if the person's level of alertness remains impaired.

### **Partial seizures**

Partial complex seizures may involve loss of awareness, inappropriate verbal response, purposeless movement, staring or repetitive chewing, swallowing or lip-smacking motions.

Simple partial seizures are involuntary jerking or shaking of one part of the body without loss of consciousness. These may spread to other body parts and become generalized.

In this situation:

- Do not try to restrain the person unless safety is jeopardized.
- Try to remove nearby hazardous or harmful objects.
- Arrange for someone to watch the person until full awareness returns.

Medical assistance generally is not necessary when partial seizures occur except when one seizure follows another in a continuous series, or when a partial seizure develops into a generalized seizure and the person is not recovering.

Even if your loved one develops seizures following acquired brain injury, your health care team will work with you and your family member on treatment options to effectively manage the seizures.

### **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, when stretched, a spastic muscle does not easily relax. Instead, the muscle remains stiff or perhaps non-moveable.

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 a lifelong process. Treatment varies depending on the person's age, severity of symptoms, and related conditions or complications. Your loved one's health care provider can provide more information.

## **Swallowing**

Problems that affect swallowing (dysphagia) may occur after brain injury.

Swallowing is coordinated by the brainstem and the brain's frontal lobes. The brainstem, which connects the brain to the spinal cord, relays messages to and from the swallowing structures (mouth, tongue, throat). The brain's frontal lobes control the muscle action of the swallowing structures.

Problems that affect swallowing after brain injury can vary widely and may include one or more of the following:

- Poor head or upper body control
- Decreased lip and tongue strength, range of motion and coordination
- Impaired memory or concentration
- Any or all of the above may cause aspiration (inhaling food or liquid into the lungs)

If a person seems to have trouble swallowing, a clinical swallowing evaluation and videofluoroscopy (a videotaped X-ray of the swallowing process) may be done. With test results, decisions can be made about treating any swallowing problems.

A person who has trouble swallowing, may need nutrition through a nasogastric or gastrostomy tube (feeding tube in the nose or stomach). Having either tube does not rule out the possibility of eating by mouth, but ensures proper nutrition and hydration (fluid intake). How long the tube is in place depends on the person's progress.

Exercises, treatment techniques and positioning may help improve a person's ability to chew and swallow. An occupational therapist or speech therapist will teach the person with brain injury and caregivers how to perform these exercises and techniques. As a caregiver, your encouragement and help with the swallowing program are essential. Most people regain the ability to swallow after brain injury, though it may take longer for some than others.

### **Bowel and bladder changes**

Brain injury may affect bowel and/or bladder function. The injured person may need help re-establishing and maintaining a pattern of regular bowel and/or bladder emptying.

#### **Bowel management**

The goals of bowel management include establishing a regular emptying pattern, maintaining dry, healthy skin, and avoiding incontinence, diarrhea, and constipation. Each person is assessed by a physician and recommendations are made as needed.

Bowel problems can occur if the person with brain injury cannot:

- Control bowel emptying voluntarily
- Recognize bowel fullness and the need to have a bowel movement
- Ask for help to the bathroom
- Walk to the bathroom
- Eat enough food with fiber and drink enough fluids
- Plan ahead and allow enough time to get to the bathroom

To maintain optimal bowel function, a person with brain injury should eat at regular times, focus on eating foods with fiber, drink the amount of fluids recommended by the dietitian or physician, and be as active as possible. Meeting with a dietitian to discuss a diet plan may be helpful. The person also may be asked to follow a bowel care schedule, which includes attempting to schedule a bowel movement at the same time daily and establishing regular times for meals.

At certain stages of recovery, your loved one may need to use other methods for bowel emptying (fiber supplements, stool softeners, suppositories, and/or laxatives). These methods typically are not used regularly because they decrease the colon's natural abilities, and these methods may be habit forming. Most individuals with brain injury regain the ability to regularly and effectively empty their bowels.

#### **Bladder management**

People with brain injury also may have a problem with urination (bladder emptying) during the post-injury period. Difficulties with urination that were present prior to the injury (an enlarged prostate in men or a pattern of infrequent urination in men or women) may add to bladder problems after brain injury.

The goals of bladder management include preserving kidney function, preventing incontinence (accidental urination), preventing bladder overfilling and bladder infections, establishing a regular pattern of urination with complete bladder emptying, and maintaining dry, healthy skin in the genital area.



Problems with bladder management may include:

- Urinary retention (an inability to void or pass urine)
- Urinary incontinence
- Increased urgency to urinate
- Increased frequency of urination
- Incomplete emptying of the bladder
- Bladder infections
- Skin problems because of incontinence

The most common reason for bladder problems after brain injury is damage to the frontal lobe of the brain. A less common cause is direct damage to the part of the brain that controls behaviors and memory. Damage to these areas may result in the inability to:

- Ask for help
- Control urination
- Recall when last urination occurred
- Plan ahead to get to the bathroom
- Walk to the bathroom in time
- Recognize the sensation of bladder fullness or the need to urinate

Early in the care of someone with brain injury, the bladder may be drained continuously through an indwelling catheter (a tube that is inserted and left in the bladder). The urine empties through the catheter into a drainage bag, which also allows for accurate recording of urine output. As the patient improves, the catheter usually is removed.

If the person cannot sense the need to urinate, other approaches to bladder management are considered, including:

- Keeping the indwelling catheter in the bladder
- Intermittent catheterization (inserting and removing a catheter several times a day to regularly empty the bladder)
- Scheduling attempts at urination
- Using an external condom catheter for men
- Using an adult diaper
- Other methods of bladder retraining to control urination may be recommended

To maintain optimal bladder function, a person with brain injury should drink fluids as recommended by the dietitian or physician. It may be helpful to meet with a bladder therapist to develop an individual plan. The majority of individuals with brain injury regain the ability to regularly and effectively empty their bladder.

# *Life After Brain Injury*

Illness or injury to a family member affects the whole family and those close to them. If the illness is chronic, the usual family roles, routines and responsibilities may be interrupted or changed. 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?

## **Going home**

The process of rehabilitation begins in the hospital and continues at home. Outpatient therapy usually lasts considerably longer than inpatient therapy. Members of the health care team will develop rehabilitation goals that optimize the abilities of the person with brain injury. Having realistic goals and expectations for yourself as a caregiver is important throughout the recovery process. Remember that the rehabilitation team is available to answer your questions and to encourage you during the adjustment to life at home with a loved one who has a brain injury.

## **Relationships**

Providing companionship and emotional support for the person with a brain injury may be necessary, in addition to physical care. Caregivers also may have many other responsibilities, including employment outside the home and caring for the home and children. Being a caregiver can be overwhelming, and adapting to these changes is challenging.

Seeking appropriate community-based social support can help lessen stress and loneliness. Many communities have brain injury support groups and centers for independent living that can help make connections with other people who have similar concerns and needs.

These suggestions may help you as a caregiver and enable you to strengthen your relationship with the person who has the brain injury:

- **Ask for help when you need it.** Caregivers frequently try to handle everything alone. Expecting too much of yourself may add to the stress. Do not be afraid to ask for help. Find options for assistance such as home health care or respite care.
- **Set limits.** There are only so many hours in the day and only so many things you can do. Some things can wait.
- **Plan something to look forward to each day.** Reward yourself for caring.
- **Take time away from the person you are caring for.** Taking an hour, a day, a weekend or a week away can do wonders to restore your emotional well being.
- **Maintain contact with friends and family** to discuss your concerns or have fun.
- **Take care of yourself.** Caregivers are vulnerable to stress-related illnesses. If you are concerned about your health, make an appointment with your physician. Inform the physician about your situation.
- **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** such as breathing exercises, meditation or progressive muscle relaxation.
- **Join a support group.** Support groups are an outlet for sharing problems and concerns. People with similar issues understand what you are feeling.
- **Keep your sense of humor.** Laughter is a great stress reducer because, for a moment, you are not focusing on problems.

## **Sexuality**

Love, affection and sexual feelings are healthy human desires. If these desires are not understood or expressed, confusion, distress and feelings of inadequacy may result. Sexuality involves the expression of male or female identities through sexual actions, attitudes and behavior in relationships. From childhood on, we become aware of sexual differences. We are taught directly and indirectly how to behave with the opposite sex.

The ability to appropriately express these learned behaviors may be lost after a brain injury. The adult with brain injury may not understand when it is appropriate to kiss, hug and touch you or other people.

Addressing your relationship with your family member should be done early in the rehabilitation process. You may find yourself in a parent role with an adult person or spouse. You may be perplexed by changes in your partner, who may act differently after the injury. Feelings of confusion, anger, fear, frustration and helplessness are understandable.

Talking about your feelings with a member of the rehabilitation team or someone you trust may help. Although at first you may feel uncomfortable discussing sexual matters, rehabilitation team members understand your feelings. The goals of rehabilitation for the person with brain injury include independence, self-reliance and healthy personal relationships. The ability to develop and maintain social relationships may be the most important measure of successful rehabilitation. Therefore, recognizing and discussing concerns about love and sex are important.

Most people have difficulty talking about sex. The closest family member of a person with brain injury is usually the most effective person to help the injured person relearn how to express sexual feelings appropriately. This family member may benefit from professional support and guidance in addressing sexual issues.

A person with brain injury who cannot recognize sexual cues, may not respond to a partner. The injured person may not initiate sexual activity. You may have to be more direct in sexual communication. Providing directions and cues are ways to reach your partner. Social workers, rehabilitation nurses and rehabilitation psychologists are resources for support in addressing sexual issues and concerns.

## **Driving**

A person with a brain injury may have physical, thinking, perceptual or vision impairments, or seizures that make driving unsafe. Driving laws vary from state to state. In some cases, the person with brain injury may be required to pass written and behind-the-wheel driving examinations before resuming driving.

The privilege of driving may be restricted or revoked temporarily, or in some cases even permanently. Talk with your loved one's health care provider if you have questions about his or her driving ability.

## **Returning to Work\***

Can a person return to work after a brain injury? The answer depends on the person and the extent of the injury. A brain injury can cause many changes in behavior, emotions, communication, and thinking skills. Keeping a job may be difficult, even the same job held prior to the injury. Regardless of whether the person with a brain injury returns to work, discovering how best to use talents will make life more rewarding. Paid employment or volunteer or leisure activities may be options.

Work (defined as productive activity) plays a major role in most people's lives. Work provides a sense of achievement, recognition, responsibility, financial independence, social interaction and structure. Those who return to work after brain injury become generally healthier and have a higher self-esteem than those who do not.

Returning to work after a brain injury depends on:

- Availability of jobs
- Health
- Desire to work
- Physical abilities
- Ability to adjust to changes
- Social and behavioral abilities (for example, control of behaviors and getting along with co-workers)
- Thinking and problem-solving abilities
- Self-awareness of deficits and limitations
- Vocational interests and capabilities
- Willingness to receive further training
- The willingness of an employer to adapt the job or workplace to the injured person

\* See Appendix D: "Americans with Disabilities Act." Refer to brochure, "Understanding Brain Injury: A Guide for Employers."

Some state agencies can help people with disabilities reach their vocational goals. The agencies' services may include physical and vocational evaluations, training, help with assistive devices, transportation and finding jobs. They work with the rehabilitation team to determine what employment is the best fit for the person.

Returning to work after a brain injury can be challenging and rewarding. Interests, aptitudes and financial options must be considered. The rehabilitation team will make every effort to help the injured person regain or develop job skills.

The vocational case coordinator employed by the Brain Rehabilitation Program can assist you with concerns or questions about brain injury and returning to work. Contact the vocational case coordinator at 507-255-3116 for assistance.

### **Returning to School**

For children and teenagers, returning to school is important for social and educational growth. At school, in addition to learning, young people find friends and peer support and develop social skills. School also provides a place to monitor children's intellectual and social growth. Sometimes the effects of a brain injury are not initially apparent in young children but become more noticeable later when thinking and social demands increase at school.

School systems have special programs to help students with disabilities return to school. Most schools have trained special educators. However, not all special educators are familiar with the needs of people with brain injury.

In some states, a brain injury educational consultant is available through the Office of Special Education. This consultant will help special educators in local schools to assess and provide services to students with brain injuries. If someone who specializes in education after brain injury is not available through the school system, members of the rehabilitation team often consult with schools and help local educators develop an educational plan to meet the injured student's academic needs.

For those returning to high school and college, developing specific accommodations can help the person with brain injury be successful in school. In most colleges, an office for students with disabilities assists in assuring that teachers provide such accommodations.

Some common accommodations to assist with learning are:

- Extra time for tests to compensate for slowed thinking or information processing
- Tests given privately in a distraction-free environment to accommodate for difficulties with attention, concentration and increased distractibility
- Placement in classrooms with less noise and distractions
- Tape recording lectures to compensate for attention, concentration and memory problems
- Access to teachers' or peers' class notes to compensate for difficulty in dividing attention between listening to a lecture and taking notes
- Assignments provided in writing to compensate for memory and concentration problems
- Providing a place to rest or take breaks to compensate for fatigue and increasing frustration
- Tutoring with a peer or a professional

In many cases, parents and family members become advocates who assure that the student with brain injury receives the necessary services to successfully return to school. Parents and family members also serve as go-betweens to make sure that rehabilitation professionals and school personnel meet to develop a plan for successful return to school. Members of the brain rehabilitation team are prepared to assist parents and families in these efforts and to acquaint them with resources available through the school system and state government.

### **Recreation and Leisure**

Participation in meaningful leisure experiences is essential to the recovery of the person with a brain injury. Most people naturally select certain activities that they enjoy and help them meet some basic needs. People with brain injuries may face barriers to experiencing this kind of fulfillment, including:

- Attitude (some people may not realize the importance of leisure activities)
- Physical disability (they may no longer be able to enjoy the activities they once did)
- Lack of cognitive skills (skills needed to participate in some activities — attention, concentration, initiation, planning, problem solving — may be impaired)
- Interruption of social and/or language skills
- Lack of knowledge (some may not know how to engage in certain leisure activities or how to adapt them so they can participate)

Family members can help by:

- Helping the person identify leisure interests
- Assisting with structuring time and daily schedules so that leisure balances with necessary tasks and activities
- Planning ahead for recreation to keep life interesting
- Investigating community resources (city parks/recreation departments, libraries, churches, and other avenues for leisure options)

Through leisure, basic human needs are met, including:

- Feeling good about ourselves
- Being part of a group
- Competing with ourselves and with others
- Experiencing success
- Laughing and having fun (reducing stress)
- Developing useful skills
- Developing friendships
- Strengthening social relationships

### **Use of Alcohol and Drugs**

A brain injury can affect how people think and manage emotions. If a person with brain injury drinks excessive alcohol, uses illicit drugs or prescription drugs in excess, those substances can further interfere with thought processes and can result in serious damage to the cells and nerves in the brain. Consequently, the effects of brain injury become worse. Family members play an important role in helping the person with a brain injury comply with physician recommendations about using alcohol and drugs.

To provide support, family members must:

- Take substance abuse seriously and avoid thinking of it as being a “phase”
- Help motivate the person to lead an alcohol-free and drug-free lifestyle
- Assist the person in developing plans to cope with situations that have resulted in alcohol and illicit drug use in the past
- Rehearse ways to avoid or react differently to such situations so that future abuse can be prevented.

Rehabilitation professionals strongly recommend that a person with brain injury avoid drugs or medications if recommended by a physician, including alcohol and cigarettes. A rehabilitation psychologist, social worker or chemical



dependency specialist can help assess whether a drug or alcohol problem exists. Alcohol and other drug treatment programs are available to help a person with brain injury recover from chemical dependency. Talk to any rehabilitation team member or physician if you have concerns about your relative about the use of alcohol and drugs.

Alcohol and drugs can trigger seizures and disturb:

- Alertness and concentration
- Self-awareness
- Perception
- Memory and learning
- Reasoning, planning and problem-solving
- Judgment
- Speech and language
- Motor control
- Emotions
- Social interactions or social behavior
- Motivation

### **Activity Restrictions**

For safety, the health care team may recommend activity restrictions. Avoiding additional brain injury is especially important.

When to return to certain activities will depend on the health care provider's recommendations and on factors such as the person's balance, strength, reaction time and judgment. The health care provider may recommend that the person not participate for a time in contact sports (such as football or hockey) or other activities that risk another brain injury (such as driving, using power equipment, climbing, rollerblading, downhill skiing, snowmobiling or riding a bicycle or horse).

For safety, be sure the person:

- Uses a seat belt when riding in a motor vehicle
- Follows activity restrictions specified by the health care provider
- Wears a helmet if participating in sports or activities for which a helmet is available

## *Available Resources*

Mayo Clinic is closely linked to the Rochester community and the region. Mayo also is affiliated with Mayo Health System, a growing network of regional care facilities. Mayo Health System practices are located in more than 50 other communities in southern Minnesota, western Wisconsin and northern Iowa.

When a person with brain injury is discharged from Saint Marys Hospital, a variety of community-based services provide ongoing support to encourage independent living.

People with brain injuries and their families often access these community resources for support:

- Residential housing assistance
- Vocational assistance and training
- Chemical health services
- Mental health services and counseling
- Legal help
- Financial consultation
- Leisure and recreation groups
- Support groups
- County and state social and human services

Because Mayo maintains strong relationships with these community services throughout the region, Mayo Clinic staff can provide information about groups and organizations that may offer further assistance.

The Brain Injury Association, Inc. is an important resource available for people with brain injuries. This national, non-profit organization, dedicated to brain injury prevention, research, education and advocacy, can be reached by calling 800-444-6443, or by visiting the following Web site at: [www.biausa.org](http://www.biausa.org).

Minnesota, Iowa and Wisconsin have state affiliates of the Brain Injury Association. These affiliate organizations operate programs and services that connect brain injury survivors, their families and friends, health care professionals and communities. The following organizations welcome your inquiries for program and support group information.

**Brain Injury Association of Minnesota**

Telephone: 612-378-2742  
800-669-6442

Web site: [www.braininjurymn.org](http://www.braininjurymn.org)

**Brain Injury Association of Iowa**

Telephone: 800-444-6443

Web site: [www.biaia.org](http://www.biaia.org)

**Brain Injury Association of Wisconsin**

Telephone: 262-790-9660  
800-882-9282 (in state)

Web site: [www.biaw.org](http://www.biaw.org)

# *Contacting Health Care Providers*

If you have questions about your loved one's condition or about this information, call Mayo Clinic and ask for your loved one's health care provider.

**Mayo Clinic: Rochester, Minn.**  
507-284-2511

# Appendix A

## A Partnership Approach

The following information outlines thinking and behavioral management strategies that may help you and the person with brain injury compensate for the loss of certain skills.

A person who has experienced a brain injury may feel a loss of control in many aspects of life. The person may feel inferior or unequal as a partner in a personal or working relationship. A partnership approach can be effective in negotiating the thinking and behavior problems of a person with the injury. After brain injury, it is important for families, those close to the family and the person with brain injury to work together as partners to develop solutions to thinking and behavior problems through the following steps:

1. Prepare a plan of action.
  - Involve the person with brain injury in the planning.
  - Define responsibilities.
  - Use compensation tools such as calendars and notebooks as memory aids through the planning phase.
2. Keep it simple.
  - Break tasks into small steps.
  - Keep the environment free of distractions.
3. Use a problem-solving format. (*Refer to Appendix C: Problem Solving Worksheet*)
  - Recognize that a problem exists.
  - Define the problem.
  - Decide on possible solutions.
  - Weigh the advantages and disadvantages of each possible solution.
  - Pick a solution.
  - Try the solution.
  - Evaluate its success.
  - Try another solution if the first one does not work.
4. Provide feedback and reassurance.
  - Evaluate performance and provide gentle, realistic comments about behavior
  - Identify successes and be matter-of-fact about mistakes.
  - Be honest, supportive and respectful.

# *Appendix B*

## *Memory and Organizational Aids*

Memory aids can provide greater independence for a person with a brain injury.

### **Calendar**

Use a calendar to plan and organize daily activities, step by step. A calendar can serve as a useful memory aid to record events, plan ahead and review successes. It can also be a reminder about uncompleted tasks and a storage site for information.

Organize the calendar for easy reference. Record any information that may be needed more than once, such as medical and vocational contacts, addresses, phone numbers, detailed information for calendar entries needing more explanation and directions in a separate, designated section. This section will make finding the information easier in the future. The calendar can also include medical information, including the names of health care providers, telephone numbers and medications with their dosage and purpose.

Wednesday FEBRUARY 26		Wednesday FEBRUARY 26	
Things To Do	Time	Description	
✓ Make bed	8	8:30 - Catch bus #2 to work	
Do laundry	9		
Make dentist appointment	10	20 minute work break	
	11		
	12	12:30 - lunch with Rob	
	1		
	2		
	3	Ride bus #9 to hospital for speech therapy	
	4		
	5	Go for walk before dinner	

Notes:

## **Cue Cards**

Cue cards can remind a person 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
- Keep it simple



# Appendix C

## Problem-Solving Worksheet

1. Define the problem. \_\_\_\_\_
2. Define possible solutions.
3. Weigh 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 does not work.

# *Appendix D*

## *Americans with Disabilities Act*

Brain injury is considered a form of disability and is covered by the provisions of the 1990 American Disabilities Act (ADA). The ADA prohibits private sector employers who employ 15 or more individuals and all state and local government employers from discriminating against qualified individuals with disabilities in all aspects of employment.

The ADA includes a workplace clause, which requires employers to provide “reasonable accommodations” for employees with disabilities. Reasonable accommodations might include making work areas accessible, allowing flexible work schedules, and re-assigning some tasks to others. However, employers are not required to make accommodations that would cause them undue hardship. In addition, employers are not required to hire people who are unable to perform the requirements of a job.

The ADA contains a broad definition of disability: A physical or mental impairment that substantially limits one or more major life activities. The ADA does not contain a list of medical conditions that constitute disabilities. Accommodations are not based on the diagnosis, but on the specific impairment.

If a brain injury has led to impairment in a major life activity, such as work, the person may be eligible for accommodations under the law. To help determine if a person with brain injury meets the ADA’s definition of disability, visit “Definition of the Term Disability (EEOC Guidance) at <http://www.eeoc.gov/policy/docs/902cm.html>

It is important for the person with brain injury to discuss accommodation needs with the employer. Some employers will accommodate employees who do not meet the ADA definition of disability.

## *Summary*

A family member's brain injury affects the whole family. Family roles, routines and responsibilities may be interrupted or changed. Often an adjustment is required in the lifestyle and interpersonal relationships of the injured person and family.

This booklet provides some possible solutions or options that may encourage families to develop their own unique solutions. Often, a brain injury psychologist, clinical social worker or other behavior specialist can help analyze and develop an approach that considers the special features of your situation.

Members of the brain rehabilitation team can help you identify ways to adjust to brain injury.

# *Notes*

# *Notes*

# *Notes*



#### BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal patient of Mayo Clinic for more than 40 years. She was a self-made business leader who significantly expanded her family's activities in oil, gas and ranching, even as she assembled a museum-quality collection of antiques and fine art. She was best known by Mayo staff for her patient advocacy and support.

Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic. Mrs. Lips had a profound appreciation for the care she received at Mayo Clinic. By naming the Barbara Woodward Lips Patient Education Center, Mayo honors her generosity, her love of learning, her belief in patient empowerment and her dedication to high-quality care.



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