

Working Together:
Your Guide to
Brain Injury
Rehabilitation
at Gillette



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This guide will provide you with information on the following topics:

- **Understanding the Brain**
- **Acquired Brain Injuries**
- **Your Child's Rehabilitation Stay**
- **Your Child's Care**
- **Planning to Go Home**

Ask Us!

Your time at the hospital will be busy and you'll have many questions. Please don't hesitate to talk with your child's health care providers about your questions or concerns.

We've developed this guide to help you understand what to expect in the weeks and months ahead. We know that this is an overwhelming and difficult time, but you don't have to go through it alone. We're here to support you. This guide contains information that will be useful both during your child's hospital stay and once you return home.

Inpatient Rehabilitation at Gillette

After a brain injury, children typically spend several weeks at Gillette for inpatient rehabilitation. During that time, we provide highly specialized medical care and therapy services to help your child become stronger and regain skills. Whatever the severity of the injury, we identify your child's strengths and challenges.

Some children might recover abilities, relearn skills and eventually return to regular activities. Others with more severe injuries might learn to adapt to physical and cognitive challenges with new strategies and routines. Please turn to the **Your Child's Rehabilitation Stay** section for specific information about your time at Gillette.

Family Conferences

In addition to talking with you every day, we'll plan family conferences about every two weeks. Family conferences offer a chance to talk with the care team about your child's progress.

Checklist

This checklist might be a useful guide through your hospital stay and transition to home.

At the Beginning of Your Child's Hospital Stay

- Gather and complete paperwork for Medical Assistance (MA), the Tax Equity Fiscal Responsibility Act (TEFRA) and other financial resources.
- Contact your insurance case manager to learn about (and understand) your insurance plan, benefits, caps, etc.
- Complete the home accessibility assessment.
- Sign the permission form so you can begin planning for school re-entry.
- Learn about resources for counseling and/or support groups.
- Attend the initial family conference and discuss diagnosis and prognosis with your health care provider.

In the Middle of Your Child's Hospital Stay

- Assess and explore home equipment needs (such as wheelchair, bathing, toileting, bed, lift, stander, etc.).
- Explore community and financial resources.
- Learn how to do car transfers and/or explore transportation needs, if required.
- Assist with cares (bowel management program, transfers, dressing, etc.).
- Explore outpatient therapy sites.
- Explore eligibility for and availability of home health care resources.
- Consider home modifications or alternative housing options, if necessary.

Toward the End of Your Child's Hospital Stay

- Select and order equipment.
- Select an outpatient therapy site.
- Select home health care agency and establish home-care plan, if needed.
- Go out on a therapeutic overnight pass, if allowed by insurance.
- Complete home modifications (short-term modifications needed before discharge).
- Follow up on potential resources for counseling and support groups.
- Complete all hands-on learning with nursing and therapists.

How Do I Prepare for My Child's Discharge?

We start planning for discharge as soon as your child enters our hospital. From the beginning of your child's hospital stay, we'll prepare your child and family for life outside of the hospital. We'll discuss how long your child might be in the hospital and explain what services and equipment your child might need after leaving the hospital.

We'll help prepare you and your child for returning to school, and if needed, for special education support services. We'll also help you think about long-term concerns, such as health insurance and transportation.

Our goal is to build a strong network of support for your child and family before it's time to leave Gillette. Turn to the **Planning to Go Home** section for specific information about leaving Gillette.

How do I find information about _____?

Topic Resource

Who do I talk to about _____?

Topic

Name of person/Contact information

“When you think of a question, write it down right away.”

– A Gillette Parent

How Will My Child Change?

Regardless of its cause or severity, a brain injury can lead to changes in physical, cognitive and social abilities. Some changes show up right away. Other changes might not reveal themselves for months, or even years. Some problems improve or even go away over time. Others might remain an ongoing part of your child's life.

Understanding the Brain

Parts of the Brain

When one or more areas of the brain are injured, the injury might change the way your child moves, thinks or speaks. Knowing how various parts of the brain work can help you better understand how your child's injury might affect behavior and abilities.

The brain is made up of billions of nerve cells that are arranged in patterns. These cells are like wires that continuously interact to send and receive messages about thought, emotion, behavior, movement and sensation. Brain injuries can disrupt nerves so that they can no longer communicate.

The brain controls all of our movements and our cognitive and social functioning. Each part of the brain has a specific role.

Cerebral Hemispheres

The two halves of the brain are called cerebral hemispheres. They work together to control the body's ability to move and think. The hemispheres look nearly the same, but they have different functions.

The **left side** of the brain controls movement and sensation in the right side of the body. For most people, it also directs:

- Verbal functioning, including speaking and understanding language
- Thought processing
- Word memory

The **right side** controls movement and sensation in the left side of the body. For most people, it also directs:

- Nonverbal functioning, such as pattern recognition, map-reading and musical enjoyment
- Expressing and understanding emotions

Lobes

The brain's hemispheres are divided into four separate areas called the frontal, parietal, temporal and occipital lobes.

Frontal lobes are involved in attention, behavioral control and planning. These lobes receive information (including memories) from other parts of the brain and help in decision-making. If the frontal lobes are injured, your child might have difficulty:

- Talking
- Paying attention in school
- Controlling emotions and impulses
- Knowing what to do if he or she gets lost
- Making decisions and judgments

Parietal lobes receive information about touch from the skin, muscles, tendons and joints. The lobes help convey information about the body's position and movement. Injuries to the parietal lobe might result in problems with drawing, copying, dressing and mathematical calculations. If the parietal lobe is injured, your child might have trouble:

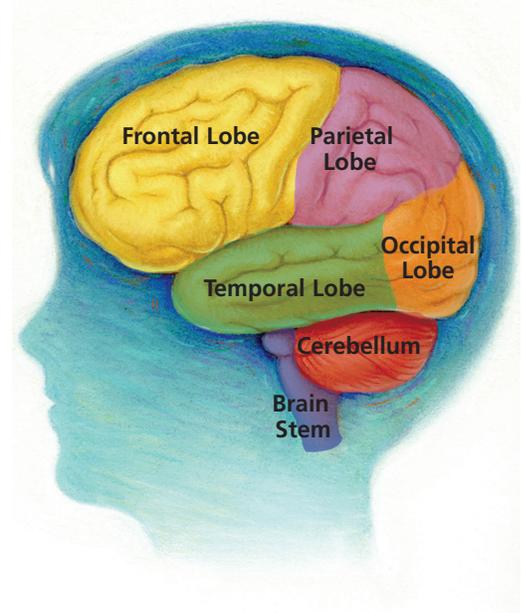
- Recognizing familiar faces
- Knowing the difference between left and right
- Doing step-by-step tasks, such as dressing
- Knowing if something is hot, cold, sharp or dull
- Completing puzzles or playing games
- Moving around without running into things
- Doing schoolwork

Temporal lobes are important to memory, emotional responses and language comprehension. If the temporal lobe is injured, your child might find it difficult to:

- Know the difference between acceptable and unacceptable behavior
- Recognize surroundings
- Know if he or she is in danger
- Remember names
- Recall what he or she did yesterday
- Understand what people are saying
- Enjoy listening to music
- Do things in the right order (such as, tying shoes and getting dressed)

Occipital lobes receive, interpret and send visual information. Injuries to this area can have an intense impact on reading and visual perception. If the occipital lobes are injured, your child might have difficulty:

- Seeing things around himself or herself
- Recognizing people
- Recognizing numbers and letters
- Reading



What Does a Brain Injury Do?

Brain injuries can disrupt nerves so that they can no longer communicate.

Cerebellum

The cerebellum coordinates muscle movements. If the cerebellum is injured, your child might have trouble:

- Walking and balancing
- Coordinating movements smoothly

Brain Stem

The brain stem receives signals from the spinal cord and nervous system. Injuries to the brain stem affect the autonomic nervous system, which controls breathing, heart rate and blood pressure. Injuries might affect your child's level of alertness, attention, and consciousness and could result in prolonged coma. If the brain stem is injured, your child might:

- Need a ventilator to breathe
- Sleep during the day or stay awake during the night
- Have difficulty keeping cool or staying warm

Limbic System

The limbic system, which is deep within the brain, is made up of four structures that regulate emotion, hormones, perception, motivation, memory and learning. If your child has damage to the limbic system, your child often has difficulty:

- Remembering information
- Regulating and understanding emotional responses (such as fear and aggression)

Cranial Nerves

These nerves carry information from the brain to other parts of the body. They are necessary to the senses of smell, taste, hearing and vision and control the muscles of the eyes, face, neck, tongue, heart, lungs, mouth, throat and digestive tract. If your child has a cranial nerve injury he or she might have difficulties with speech, eating, facial movement, sight, hearing and motion sickness.

REHABILITATION STORIES

Sophia, 2½

Sophia fell from a second-story window. It was not clear whether she lost consciousness. She had a number of skull fractures and bleeding on the right side of her brain.

After she was stabilized, Sophia was in rehabilitation for 10 days. She had weakness on the left side of her body from the bleeding in her brain and had difficulty with balance. In rehabilitation she worked on improving her strength and balance.

Three years after her fall, she has developed age-appropriate skills in many areas. Her attention to and persistence with tasks varies. She has lost some ground with her speech skills. Her development will continue to be closely monitored.

Rebekah, 16

Rebekah was in a car accident. She had facial and skull fractures. The impact to her skull caused bleeding on both sides of her brain. The injury also damaged nerves that help her control facial and eye movements.

After two weeks in intensive care, Rebekah spent two months in intensive rehabilitation. She had a tracheostomy tube for breathing and a gastrostomy tube for nutrition. She was dependent on others for all of her care.

During rehabilitation, Rebekah improved in all areas, including her ability to walk, talk and perform her daily routine. She still struggled with concentrating, remembering new information and expressing herself.

When Rebekah returned home she went to out-patient therapies and followed a modified school program. She continued to improve in all areas with significant support from her family.

Five years after her accident, Rebekah has participated in a transition program to prepare for college. She requires support for reading and note taking, and accommodations for test taking. Rebekah has strong speaking skills and a great vocabulary.

As a young adult, Rebekah still needs support to ensure that she's making safe decisions.

Acquired Brain Injuries

There are different types of brain injuries. An acquired brain injury happens after birth and damages the brain. The injury either results from an outside force (traumatic brain injury), from changes within the brain (non-traumatic brain injury), or from a lack of oxygen to the brain (anoxic brain injury).

Traumatic Brain Injuries

Traumatic brain injuries (TBIs) occur when an external physical force causes an injury to the brain. The force might jerk the head back and forth, causing the brain to tear and/or bruise as it bumps against the inside surface of the skull. The force might involve an object breaking through the skull, injuring the brain directly. If there is a skull fracture, a fragment of the skull might cause damage to the brain. TBIs typically damage some areas of the brain more than others.

Types of Head Injuries

Closed-head injuries are often caused by accidents, falls or assault. These are the most common type of TBI and can cause scattered damage to the whole brain.

Open-head injuries, such as gunshot wounds or falls onto sharp objects, are caused by objects that penetrate the skull.

Since the brain is not rigidly attached to the skull, it moves inside the skull when there is a force to the head. Damage to the brain is caused by twisting, compression, stretching or shearing. The force might make the brain hit the opposite side of the skull and cause further injury.

Diffuse Axonal Injury

This injury results from the brain moving back and forth in the skull as a result of acceleration, deceleration or rotation. The injury doesn't have to be due to impact. For example, automobile accidents, sports-related accidents, violence, falls, and child abuse, such as Shaken Baby Syndrome are common causes of diffuse axonal injury. The injury can be responsible for prolonged unconsciousness or ongoing lower levels of consciousness that occur after a severe traumatic brain injury.

Possible Outcomes

After a traumatic brain injury, it's often difficult to predict how children will recover or to what extent they'll regain the ability to walk or talk. Here are some details about what to expect:

- Most improvement occurs during the first six months after injury. However, most children continue to improve for 12 months or more.
- A child who is unable to talk six months after an injury might still regain speech after 12 months, although the child's speech might be difficult to understand.
- A child who needs to use a wheelchair at six months might walk with a walker 12 months after the injury.

The best predictor of how well children will do is the length of time they are unconscious. The less time a child is unconscious, the better the prognosis.

Unconscious Less than Seven Days

Children who are unconscious for less than seven days almost always recover the ability to talk and walk. Many also regain the ability to function independently at home, including independent self-care skills, such as dressing, going to the bathroom and performing personal hygiene. These children might have subtle difficulties with memory, attention and judgment. Some children might struggle in school because these difficulties might interfere with their ability to learn and apply knowledge. They might require some accommodations at school for some time following the injury.

Unconscious One to Four Weeks

Most children who are unconscious for around one to four weeks, eventually learn to walk and talk again. They also regain independence in self-care skills, such as dressing, going to the bathroom and personal hygiene. However, because these children usually experience learning problems, they often require special-education services when they return to school.

Unconscious Five to 12 Weeks

Approximately one-third of these children regain the ability to walk independently, one-third learn to walk with leg braces or a cane, and one-third will use a wheelchair. Most of these children can communicate verbally, but have some problems with speech and language skills, as well as cognitive abilities (thinking). They can have significant difficulties with memory, learning new information and organization. These children will need special education services when they return to school.

Some children with traumatic brain injuries are still unconscious when they're discharged from Gillette. Many will continue to change after discharge and some emerge from unconsciousness after they go home. However, these children typically have significant problems with cognitive (awareness, thinking and reasoning) and motor (movement) abilities.

What Will My Child's Recovery Be Like?

The best predictor of how well a child will do after a brain injury is the length of time he or she is unconscious.

REHABILITATION STORIES

Mark, 14

Mark's brain was seriously injured when he nearly drowned while swimming with a friend. He might have had a seizure. A few days after Mark stabilized, he was transferred to the rehabilitation unit. His speech was weak and slurred (dysarthric). Mark had trouble controlling his right hand and arm. He also struggled with balance and had vision problems.

Mark was in intensive rehabilitation for about a month. He demonstrated significant improvement in all areas. He returned to school with some special-education support.

Three years later, Mark is more able to do physical activities with his friends. He still has some coordination challenges with his right arm. His speech has improved, but he still has some mild slurring when he's tired. His seizures continue.

Mark has support in school and he often works with a tutor in the summer. He plans to continue his education after high school.

Jake, 7

Jake was playing with friends near a lake and is thought to have fallen in the water. It is not clear how long he was without oxygen. Jake sustained a severe brain injury.

When he came to rehabilitation, Jake was not very responsive. He was unable to eat and could not sit up on his own. The rehabilitation team worked with Jake's family to show them how they could help him improve these skills.

Two years later, Jake is able to sit in a wheelchair with the use of braces and a head rest. His home has been adapted to accommodate his wheelchair. At school Jake recognizes friends and teachers and vocalizes to start conversations with them. He uses a switch that plays recorded messages to help him communicate.

Jake lives with his parents and siblings and enjoys going places with his family.

Anoxic Brain Injuries

When children can't breathe—if they are underwater too long, have a cardiac arrest, are near suffocation, or have their airway blocked by a toy or food—their brain function is impaired.

When there is too little oxygen, nerve cells throughout the brain die, causing damage to part or all of the brain. This lack of oxygen to the brain causes an anoxic brain injury.

Some research indicates that the brain can be without oxygen for around eight minutes and still recover many skills. For example, children with an anoxic brain injury that occurs during a cardiac arrest where the child is without oxygen for a few minutes might show a great deal of improvement during the weeks following the accident. However, they commonly have significant problems remembering recent events. For example, they might not recall what they ate for lunch by the end of the afternoon.

Children who have been without oxygen for long periods of time generally experience more disabilities, including hyper-tonia (stiffening of the muscles) and difficulties with motor function. Their recovery also can take longer. An example of this more severe brain injury is a child who was underwater and unresponsive for 20 to 30 minutes. They might remain unconscious for long periods of time. Children who are unconscious for more than eight weeks often have very severe cognitive and motor impairments. However, many children with profound disabilities smile and respond to voices and faces.

Many children with more severe anoxic brain injuries are still unconscious when they leave Gillette. Some show subtle improvements in response to sensory stimulation or make gains in oral feeding after discharge. Others emerge into consciousness after they go home (usually within the first three months after the injury).

Possible Outcomes

Recovery after an anoxic brain injury usually depends on the how long a child was without oxygen, as well as on how the child's brain responds after the injury. If a child was without oxygen for a relatively short period of time after his or her brain was injured, he or she might learn to talk and walk again, but will likely have memory and learning challenges. The prognosis for children with more severe anoxic injuries, such as near-drowning, is more cautious.

Some children have very significant problems with cognitive (awareness, thinking and reasoning) skills and motor (movement) abilities. Children with anoxic injuries usually need special-education school services.

Non-Traumatic Brain Injuries

Non-traumatic brain injuries occur when something happens to alter the healthy functioning of the brain from within. The following conditions and illnesses might cause this to happen:

Encephalitis: An inflammation of the brain caused by a virus or bacteria.

In more severe cases, a high fever can impact the central nervous system. Brain swelling can injure various parts of the brain. Depending on where the injury occurs, children can experience learning difficulties, speech and language challenges, memory loss, reduced muscle control and balance and coordination problems. Vision and hearing may be altered. Fatigue is common. Some children also experience difficulty managing their emotions.

Meningitis: An inflammation of the membranes that cover the brain and spinal cord (meninges).

It's usually caused by bacteria or viruses. One of the most common problems resulting from meningitis is hearing loss. Other neurological problems might include visual impairment, seizures and learning disabilities. Some children might need surgery if they have difficulty circulating the fluid of the brain and spinal column (hydrocephalus).

Posterior Fossa Syndrome: A condition that some children experience after the removal of a posterior fossa tumor.

The posterior fossa is a portion of the brain that includes the cerebellum and brain stem. The signs and symptoms of this syndrome vary, but can include the inability to speak or speech that is difficult to understand. Children might have difficulty chewing and swallowing safely. Children might struggle to move their arms and legs. If the nerves of the face and neck are involved, children experience difficulty with facial expressions or opening and closing their eyes. They also might struggle to control emotions.

Childhood Stroke: Strokes might result from brain malformations, infections such as encephalitis or meningitis, trauma or blood disorders.

Depending on the cause and location of the stroke, the child might have difficulty with speech and movement on one half of the body. Communication can be severely affected if the stroke occurs in the left side of the brain. If bleeding is more severe, the child might experience epilepsy and significant cognitive challenges.

REHABILITATION STORY

Dustin, 11

Dustin was traveling abroad with his family when he became very ill with viral encephalitis. He was hospitalized abroad for around five months before he was transferred to the United States for rehabilitation.

Dustin was admitted with a tracheostomy tube and a gastrostomy tube. He was unable to control movement of the muscles in his arms, legs and face (severe dystonia). This made it very difficult for him to speak, point, sit up or walk.

Dustin and his family participated in an intensive rehabilitation stay for three months. During that time he was able to improve the control of his arms. This control allowed him to be able to point and activate a communication device.

In time, he was able to have his tracheostomy and gastrostomy tubes removed. His ability to speak slowly improved and he regained some of his ability to dress and feed himself. Dustin was able to take some steps, but relied on a wheelchair to travel longer distances.

One year after his illness, Dustin struggles with problem-solving and impulse control. He also has difficulties understanding complex sentences and following directions. When Dustin returned home he returned to the school in his neighborhood where he receives special-education services.

Today, Dustin is still recovering from his serious illness. It is likely he will continue to regain skills, but will have lifelong physical and cognitive challenges.

REHABILITATION STORY

Nikki, 8

Nikki developed a headache and had weakness on the left side of her body. She was diagnosed with having a bleed on the right side of her brain due to a stroke. A few days after Nikki was stabilized she transferred to the rehabilitation unit.

Nikki was in intensive rehabilitation for about a month. When she arrived, she was paralyzed on the left side of her body. Nikki was unable to talk and was fed through a tube. She could nod, shake her head and point to some objects.

Nikki and her family worked very hard to recover her ability to walk, talk, eat and do many daily tasks on her own. During rehabilitation, she regained the ability to write and perform other fine motor tasks like tying her shoes.

When Nikki returned home she received therapies related to her education and academics at school. She also continued outpatient therapies at Gillette.

Six months after her stroke, Nikki is continuing to make progress. However, she still faces many challenges. Her ability to process information is still slow and she finds it difficult to organize her thoughts and write them down without help.

Nikki's family, school and community continue to support Nikki in her recovery.

Arteriovenous Malformations (AVMs): Abnormal connections between arteries and veins that are present at birth.

In some cases, the AVM might bleed. Bleeding injures the brain and is considered a form of stroke. Depending on where the bleed occurs, children can experience difficulties with speech, control of their arms and legs, and with understanding and learning. For some children the bleeding in the brain might affect one side of the body. If children have a bleed on the left side of the brain, they are likely to have more challenges with communication. If the right side of the brain is affected, they might have speech, but difficulty with reasoning, problem solving, and emotional expression. They sometimes have difficulty recognizing others emotions as well.

Encephalopathy: An injury to the brain that is the result of disruption of other functions of the body.

Some examples of disruptions include:

- Illnesses that include the liver (hepatic), or pancreatic function such as diabetes.
- Disruptions to the heart that impacts the delivery of oxygen to the brain (anoxia).
- Severe dehydration (loss of fluids) or the opposite situation where water accumulates too quickly in the body.
- Environmental toxins such as leaded paint and ingestion of substances such as prescription medicines, alcohol and other drugs.

Possible Outcomes

The outcomes of children with non-traumatic brain injuries will vary greatly, depending on the cause of the injury as well as on a child's medical history. Your child's health care providers will assess your child to determine the extent of the injury and to some extent, your child's potential for recovery. The rehabilitation team will share information about outcomes of other children with similar diagnoses, but each child's response to a brain injury and recovery is unique.

Cognitive Functioning

Cognition refers to a person's thinking and memory skills. Cognitive skills include paying attention, learning new information, being aware of one's surroundings, organizing, planning, following through on decisions, solving problems, judgment, reasoning and awareness of problems. Because of the damage caused by a brain injury, some or all of your child's cognitive skills will change. Cognitive functioning is related to your child's level of consciousness. Level of consciousness is a measurement of a person's responsiveness to what is going on around them.

Your rehabilitation team will use the Rancho Levels of Cognitive Functioning to describe your child's level of consciousness and recovery. This tool helps health care providers and families discuss a child's progress. The ten levels describe the patterns or stages of recovery typically seen after a brain injury. This helps the team to understand and focus on the person's abilities and design an appropriate treatment program. Children progress at their own rates. Some will pass through each of the ten levels, while others will not.

The Rancho Levels of Cognitive Functioning		
	Your child might:	What can I do?
Cognitive Level I	<ul style="list-style-type: none"> • Not respond to sounds, sights, touch or movement 	<ul style="list-style-type: none"> • Keep a therapy journal or take photographs or videos of your child.
Cognitive Level II	<ul style="list-style-type: none"> • Begin to respond to sounds, sights, touch or movement • Respond slowly, inconsistently, or after a delay • Respond to what he or she hears, sees or feels by chewing, sweating, breathing faster, moaning, moving, and/or increasing blood pressure 	<ul style="list-style-type: none"> • Explain to your child what you are about to do. For example, "I'm going to move your leg." • Talk in a normal tone of voice. • Keep comments and questions short and simple. For example, instead of "Can you turn your head towards me?" say "Look at me." • Tell your child who you are, where they are, why they're in the hospital, and what day it is.
Cognitive Level III	<ul style="list-style-type: none"> • Be awake on and off during the day • Make more movements than before • React more specifically to what he or she sees, hears or feels (for example, turning towards a sound, moving away from pain, and trying to watch a person move around the room) • React slowly and inconsistently • Begin to recognize family and friends • Follow some simple directions such as "look at me" or "squeeze my hand" • Begin to respond inconsistently to simple questions with "yes" and "no" head nods 	<ul style="list-style-type: none"> • Limit the number of visitors to two or three people at a time. • Keep the room calm and quiet. • Bring in favorite belongings and pictures of family members and close friends. • Allow your child extra time to respond, but don't expect responses to be correct. Sometimes your child might not respond at all. • Give your child time to rest. • Engage your child in familiar activities, such as listening to favorite music, talking about family and friends, reading out loud, combing his or her hair, putting on lotion, etc. • Be careful what you say in front of your child. Your child might understand parts of what you are saying.
Cognitive Level IV	<ul style="list-style-type: none"> • Be very confused and frightened • Not understand what he or she feels • Not understand what is happening around them • Overreact to what he or she sees, hears, or feels by hitting, screaming, using abusive language or thrashing about • Be restrained so he or she doesn't hurt themselves • Be highly focused on his or her basic needs; such as, eating, relieving pain, going back to bed, going to the bathroom or going home • Not understand that people are trying to help • Not pay attention or be able to concentrate for a few seconds • Have difficulty following directions • Recognize family/friends some of the time • Be able to do simple routine activities with help such as feeding, dressing or talking 	<ul style="list-style-type: none"> • Keep a therapy journal or take photographs or videos of your child. • Tell your child where they are and reassure your child that he or she is safe. • Bring in family pictures and personal items from home, to make your child feel more comfortable. • Allow your child as much movement as is safe. • Take your child for wheelchair rides, with permission from nursing. • Find familiar activities that are calming to your child such as listening to music, eating, etc. • Listen to what your child wants to do, within safety limits. • Give your child breaks and change activities frequently. • Keep the room quiet and calm. Turn off the TV and radio, don't talk too much, use a calm voice. • Limit the number of visitors to two to three people at a time.

The Rancho Levels of Cognitive Functioning – page 2

	Your child might:	What can I do?
Cognitive Level V	<ul style="list-style-type: none"> • Be able to pay attention for only a few minutes • Be confused and have difficulty making sense of the things outside him or herself • Not know the date, where he or she is or why he or she is in the hospital • Not be able to start or complete everyday activities, such as brushing teeth, even when physically able • Become overloaded and restless when tired or when there are too many people around • Have a poor memory, your child will remember past events from before the accident better than his or her daily routine or information he or she has been told since the injury • Try to fill in gaps in memory by making things up • Get stuck on an idea or activity and need help switching to the next part of the activity • Focus on basic needs such as eating, relieving pain, going back to bed, going to the bathroom or going home 	<ul style="list-style-type: none"> • Keep a therapy journal or take photographs or videos of your child. • Repeat things as needed. Don't assume that your child will remember what you say. • Tell your child the day, date, name and location of the hospital, and why your child is in the hospital when you first arrive and before you leave. • Keep comments and questions short and simple. • Help your child organize and get started on an activity. • Bring in family pictures and personal items from home. • Limit the number of visitors to two to three at a time. • Give your child frequent times to rest. • Encourage your child to contribute to a therapy log or journal.
Cognitive Level VI	<ul style="list-style-type: none"> • Be somewhat confused because of thinking and memory problems, remembering the main points from a conversation, but forgetting and confusing the details. • Follow a schedule with some assistance, but become confused by changes in the routine • Know the month and year, unless there is a severe memory problem • Pay attention for about 30 minutes, but has trouble concentrating when it's noisy or when the activity involves many steps (for example, in the cafeteria, struggling to select foods, organize tray and pay for food without assistance) • Brush his or her teeth, get dressed, feed himself etc., with help • Know when he or she needs to use the bathroom • Do or say things too fast, without thinking first • Know that he or she is hospitalized because of an injury, but will not understand all of the problems he or she is having • Be more aware of physical problems than thinking problems • Associate his or her problems with being in the hospital and think that all will be fine as soon as he or she goes home 	<ul style="list-style-type: none"> • Keep a therapy journal or take photographs or videos of your child. • Repeat things. Discuss things that have happened during the day to help improve your child's memory. • You might need to help your child with starting and continuing activities. • Encourage your child to participate in all therapies. Your child will not fully understand the extent of his or her problems and the benefits of therapy.

The Rancho Levels of Cognitive Functioning – page 3

	Your child might:	What can I do?
Cognitive Level VII	<ul style="list-style-type: none"> • Follow a set schedule • Be able to do routine self-care without help, if physically able (for example, dressing or feeding himself or herself independently) • Have problems in new situations and might become frustrated or act without thinking first • Have problems planning, starting, and following through with activities • Have trouble paying attention in distracting or stressful situations (family gatherings, work, school, church or sports events) • Not realize how his or her thinking and memory problems may affect school, friends and family • Continue to need supervision because of decreased safety awareness and judgment • Think slower in stressful situations • Be inflexible, rigid or stubborn • Be able to talk about doing something, but will have problems actually doing it 	<ul style="list-style-type: none"> • Keep a therapy journal or take photographs or videos of your child. • Providing guidance and assistance in decision making as appropriate for his or her age. Your child's opinions should be respected. • Talk normally with your child. There is no need to try to use simple words or sentences. • Be careful when joking or using slang, because your child might misunderstand the meaning. Also, be careful about teasing your child. • Help your child with familiar activities. Talk to your child about these difficulties without criticizing. Reassure your child that the difficulties are because of the brain injury. • Strongly encourage your child to continue with therapy to increase your child's thinking, memory and physical abilities. Your child might think therapy is unnecessary because he or she feels completely normal. • Be sure to check with the doctor about your child's restrictions.
Cognitive Level VIII	<ul style="list-style-type: none"> • Realize that he or she has a problem in his or her thinking and memory • Begin to compensate for his or her problems • Be more flexible and less rigid in his or her thinking (for example, coming up with several solutions to a problem) • Be able to learn new things at a slower rate • Still become overloaded with difficult, stressful or emergency situations • Show poor judgment in new situations and may require assistance • Need some guidance to make decisions • Have thinking problems that might not be noticeable to people who did not know the person before the injury 	<ul style="list-style-type: none"> • Discourage your child from high risk activities, due to medical complications. • Encourage your child to use note taking as a way to help with his or her remaining memory problems. • Encourage him or her to carry out self-care as independently as possible. • Discuss what kinds of situations make your child angry and what your child can do in these situations. • Talk about feelings.
Cognitive Level IX	<ul style="list-style-type: none"> • Independently shift back and forth between tasks and complete them • Use assistive memory devices to recall daily scheduled "to do" lists • Initiate and carry out steps to complete familiar tasks • Acknowledge impairments and disabilities • Think about consequences of decisions or actions • Accurately estimates abilities but require stand-by assistance to adjust to task demands • Acknowledge others' needs and feelings and show improved social interaction • Have low frustration tolerance 	<ul style="list-style-type: none"> • Provide your child with a semi-structured environment, for example, allow him or her to prepare a simple meal with an adult nearby to provide guidance. • Monitor your child for safety in most environments. • Encourage use of adaptations and accommodation for memory and mental and physical fatigue during daily activities.
Cognitive Level X	<ul style="list-style-type: none"> • Handle multiple tasks simultaneously with breaks • Use memory devices • Independently initiate and carry out steps with compensatory strategies to complete familiar activities • Takes action to avoid problems with impairments • Think about consequences of decisions or actions • Recognize the needs and feelings of others • Be irritable and have a low frustration tolerance when sick or fatigued • Demonstrate social interaction behavior that is consistently appropriate 	

Your Child's Rehabilitation Stay

What's My Role in Therapy?

You and other family members play important roles in your child's rehabilitation. For example, children will sometimes respond to family members before they respond to medical staff and therapists. That's why we often involve family members in therapy sessions.

We'll work closely with you to customize your involvement in a way that balances your child's need for support with his or her need for independence. We'll also teach you how to do therapy activities with your child in the hospital and at home.

Two children who have injuries to the same part of the brain might recover very differently. The short- and long-term effects of a brain injury depend on many things. Brain injuries vary in severity and affect different parts of the brain. Some children have other medical problems and injuries that can affect healing. In this section you'll learn about the rehabilitation process and the team members that will help you through your child's care.

What Can We Expect?

Rehabilitation following a brain injury is an ever-changing process that is tailored to the needs of your child. We will observe your child closely, watching for signs of progress and increasing alertness. Rehabilitation goals and activities might change each day, depending on how your child is responding and healing. You might notice that several therapists will work on the same skill with your child, but in different contexts or for different reasons. For example, occupational therapists might work on strengthening fine motor skills for writing and psychologists might ask your child to write to practice memory skills. If you have questions about why a therapist has chosen a certain activity, feel free to ask.

How Will My Child Progress?

We encourage you to ask questions, but want you to know that after a brain injury the questions that are most important to you might not have simple answers. All parents have the following questions:

- How will a brain injury affect my child?
- What can I expect my child to achieve during rehabilitation?
- How do you monitor my child's recovery?
- What's the long-term prognosis for my child?

Although every child is different, we do know that children who never lose consciousness or who are unconscious for only a very short time usually recover more quickly. In addition, you'll usually see the most improvement within the first six months after your child's brain injury. Although children often continue to progress for a year or more, these later improvements are usually more subtle.

First Steps

In the early stages of therapy, we evaluate your child's responsiveness—the ability to listen, comprehend and interact with people and surroundings. Children with brain injuries are often tired and difficult to awaken.

Even before children are fully alert, we place them in wheelchairs or standers so we can stimulate their senses and evaluate how they react.

- Do they respond more when they're sitting?
- Are they more alert when they're standing?
- Can they follow verbal directions?
- Do they move their hands or turn their heads in response to sound?
- Are they more agitated in a busy crowded area?

If a child isn't alert, we might offer stimulation to encourage arousal and response. Stimulation therapy might include loud sounds, soft whispers, light touches and tickling. We sometimes use familiar objects to trigger memories and engage a child's sense of touch, hearing, sight and taste. For example, we might offer a ball to a child who loves playing basketball.

We also begin therapy to work on moving and strengthening your child's arms and legs before he or she is fully alert. Working with children in the early stages of recovery helps maintain and increase their range of motion.

Increasing Expectations

We want your child to have success and also to work hard in therapies each day. As your child becomes more aware of his or her surroundings, we will make his or her activities more challenging. We might, for example, take away some support while your child is sitting so that your child has to use his or her muscles and balance more. We might add cognitive challenges to increasingly difficult physical activities. One week, your child might spontaneously reach for a ball while sitting with support. A little later, we might ask your child to reach for a ball on the floor while sitting with support. Still later, we might put out several different balls and ask your child to only pick up the red ones. At first, we might use hand over hand assistance to help move an object, but we will gradually reduce our help as they gain strength and skill.

We also pay close attention to your child's responsiveness and need for stimulation or quiet. If your child needs more stimulation, we might move from a quiet room to a gym where there's more activity. If a child becomes more alert and distraction is a concern, we might move to a quieter room.

Throughout this process of observing and increasing therapy expectations, we'll work closely with you to discuss your child's progress and set new goals.

What Is a Typical Day Like?

We try to structure each day a little like a typical day at home or school. Depending on your child's abilities, your child will get up and dressed in the morning independently or with assistance. Your child will then attend scheduled therapy sessions and school. Your child will eat meals in the family room and spend time socializing with family and friends as well as with other patients.

Your child will likely participate in physical, occupational, and/or speech and language therapy every day. You might notice two therapists working with your child at the same time, like an occupational therapist and a physical therapist. Your child will also attend school daily and meet with therapeutic recreation specialists, psychologists, child life specialists and a music therapist.

Each day, rehabilitation nurses will take care of your child's medical needs. The nurses also will practice skills learned in therapy with your child. Depending on the severity of your child's injury, a routine day might also include visits with respiratory care specialists, dieticians and other care providers. A pediatric rehabilitation medicine doctor will check in with your child every day.

In the evening hours during the week and in the afternoon on weekends, child life specialists provide activities. These activities might include craft projects, games, dog shows or special group events. All children and families are encouraged to participate.

**“Be nice to your nurses.
Work together with them.
Learn from them and use
them as a resource.”**

– A Gillette Parent

Rehabilitation Team

Although people from many different medical specialties might be part of your child’s care team, the following groups of specialists will be most directly involved in your child’s day-to-day rehabilitation.

Care Coordinators

Inpatient rehabilitation coordinators schedule tours and help your child and family become familiar with the hospital and rehabilitation environment. During your hospital stay, care coordinators help you understand your child’s plan of care and help with other concerns, such as insurance coverage.

Rehabilitation Nurses

Rehabilitation nurses are specially trained to care for children and teens with complex rehabilitation needs. A rehabilitation nurse responds to your child’s medical needs, provides ongoing patient and caregiver education and reinforces the skills learned in therapies. Many nurses are certified in specialty areas such as rehabilitation, pediatrics and brain injury.

Pediatric Rehabilitation Medicine Doctors

Pediatric rehabilitation medicine doctors lead your child’s overall rehabilitation program. You might see more than one doctor during your stay. They recommend various types of therapies, orthoses (braces and splints), wheelchairs and other equipment to help your child do everyday activities. The pediatric rehabilitation medicine staff will oversee your child’s medical care throughout your hospital stay and consult with your primary-care doctors after you go home from the hospital. Your child might continue to see a Gillette pediatric rehabilitation medicine doctor after your child’s discharged.

- **Fellow**

A fellow will see your child each day. A fellow is a doctor who has completed medical school and also a residency in Physical Medicine and Rehabilitation. Fellows who come to Gillette are training to specialize in treating children with needs similar to your child’s.

- **Residents**

A resident is part of the health care team who will see your child each day. A resident is a doctor who has completed medical school and is currently training in the field of Physical Medicine and Rehabilitation.

Assistive Technology

Assistive Technology Specialists

Our assistive technology specialists design and build custom orthoses (braces and splints), wheelchair seating systems and adaptive equipment to help your child with activities such as walking, turning on a light or using a computer for school.

Child and Family Services

Chaplains

Chaplains provide pastoral care, spiritual guidance and religious resources, regardless of a family's religious affiliation. Chaplains also are available to talk with families who are facing difficult medical decisions.

Child Life Specialists

Child life specialists can help your child understand and adjust to rehabilitation through education and play. They also prepare children before medical procedures and then provide support and distraction during the procedures to help reduce anxiety. Child life specialists organize hospital activities, such as play groups and teen groups to promote social interactions among peers.

In addition, siblings can work with a child life specialist who will help them cope with having a brother or sister in the hospital and to understand what it means to have a sibling with a brain injury.

Music Therapists

Music therapy can be used to provide anxiety reduction and relaxation, distraction and support during medical procedures, sensory stimulation, leisure skill development, and an outlet for creative, emotional or spiritual expression. Board certified music therapists can produce positive change in your child's behavior, functioning, and quality of life. A music therapist will tailor sessions to meet your child's specific needs and take music preferences, interests, culture, and short and long-term goals into consideration. A music therapist will use singing, improvising, songwriting, dancing, and playing instruments and games with your child.

Pediatric Neuropsychologists

Pediatric neuropsychologists evaluate how your child's brain injury has influenced his or her cognitive functioning, such as memory, attention, problem solving and academic learning. They will provide recommendations or accommodations that might be helpful. They also address behavioral changes that might occur after an injury. By understanding how the brain affects behavior and learning, pediatric neuropsychologists can help improve your child's school performance and relationships.

**"Always ask questions.
Don't ever be afraid to ask
questions."**

– A Gillette Parent

**“Your lives continue
outside the hospital.
Remember that.”**

– A Gillette Parent

Psychologists

Psychologists evaluate your child’s cognitive, academic, psychological and social abilities and needs. They work with you and your child to develop ways to recover skills that will help improve your child’s academic achievement, mental health and social relationships.

Psychologists play a central role in preparing you and your child for the transition back to school. Throughout your child’s hospital stay, the psychologist will be in contact with your child’s school to discuss possible educational needs.

Some children experience signs of depression after a brain injury. This might be due to the injury itself, loss of function and abilities, disruption of sleep or medicines. If depression might be affecting your child’s recovery, we’ll help you and your child address those concerns.

Social Workers

Social workers regularly meet with families to provide education and support. They help families cope with the stress of hospitalization and the emotional trauma and grief that often accompany brain injuries. Social workers help you plan for when you’ll leave the hospital by finding resources, such as therapy services and equipment in your local community.

Therapeutic Recreation Specialists

Therapeutic recreation specialists use games and leisure activities to evaluate and improve cognitive and social skills. Because children who’ve experienced brain injuries might find it difficult to follow directions, they’ll begin with basic tasks and progress to more complex leisure activities. They’ll also discuss recreational and leisure activities that your child might do at home with you or in your community.

Therapeutic recreation specialists also provide ideas about adaptive equipment that might be useful as your child returns to activities your child enjoyed in the past. They provide ideas for new leisure interests as well.

Rehabilitation Therapies

Audiologists

Our audiologist tests and treats any changes in your child's hearing that occur as a result of his or her brain injury.

Occupational Therapists

Occupational therapists help your child build skills to do their daily activities, such as playing or attending school. They work with your child to help him or her become more independent by focusing on strengthening muscles and building up endurance.

Occupational therapists work on:

- Daily living skills (dressing, feeding, grooming, bathing)
- Small motor skills (writing, cutting, drawing)
- Visual motor/visual perceptual skills (using eye movement for drawing, writing, doing puzzles)
- Cognitive skills (keeping to a schedule, learning to play a new game)

They might show your child how to do activities in a new way or use adaptive equipment.

Physical Therapists

Physical therapists focus on assessing and improving your child's strength, coordination, balance, range of motion and endurance (gross motor skills). These skills help your child perform everyday tasks, such as walking, using a wheelchair and climbing stairs.

Physical therapists evaluate whether your child needs a wheelchair, an assistive walking device, a stander, or other equipment to do everyday activities.

Speech and Language Pathologists

Speech and language pathologists evaluate your child's ability to communicate, eat and swallow. They will also take a look at your child's cognitive skills such as memory, attention and problem solving. Speech therapists help determine whether physical injuries are affecting hearing, voice and breath support for speech.

Speech and language pathologists also work with children who have tracheostomies and need a ventilator to breathe.

Education

School Services

Gillette works closely with your child's school district to help your child return to school. Through Gillette's partnership with the St. Paul public schools, teachers are on-site at the hospital providing education services for your child.

"Keep working hard and pushing your child. They will thank you someday."

– A Gillette Parent

“You will get to go home.”

– A Gillette Parent

Your Child’s Care

Your child’s care team will talk to you about what to expect during your child’s short- and long-term recovery. The team will work with you and, if possible, your child to set goals for treatment. Those goals are used to develop a care plan. The plan is a guide for your child’s medical treatments and therapies. Therapists will review your child’s care plan at least once a week.

In addition to talking with you every day, the team also plans regular family conferences about every two weeks. Family conferences offer a chance to talk with the care team about your child’s progress. They also give you an opportunity to ask questions of the team as a group. See the **Checklist** and **My Questions and Notes** at the beginning of this guide. The team also ensures that the care plan continues to reflect your child and family’s goals.

Children who have experienced brain injuries can have complex medical needs. In addition to the rehabilitation team, Gillette brings together a team of highly skilled medical specialists to manage your child’s care and treatment.

Feeding and Nutrition

Nutrition is important for healing. Children who have brain injuries might have trouble eating for a number of reasons. Some children aren’t yet fully alert. Others might have injured the part of the brain which controls swallowing, chewing and hunger. Some children aren’t interested in eating. Still others might have damage in a part of the brain known as the satiety center, and might not get the same feeling of fullness when they have had enough to eat.

Tube Feedings

Children who have brain injuries sometimes can’t eat or drink on their own, particularly right after the injury. Initially, some children need feeding tubes, such as nasojejunal (NJ) tubes or nasogastric (NG) tubes. NJ tubes run through the nose and down into the small intestine. NG tubes run through the nose and down into the stomach. After a few weeks, children who are still unable to eat or drink on their own might need gastrostomy tubes (G-tubes). G-tubes go through the skin of the abdomen into the stomach. All of these tubes allow your child to get enough calories, vitamins, minerals and other important nutrients.

Transition to Oral Feedings

Speech and language pathologists determine if a child can swallow before attempting feeding by mouth. For children who are ready, our specialists give small amounts of soft food and observe their ability to manage the food and swallow safely. Then they gradually

increase the amount of regular food given. As a child begins eating more by mouth, our specialists decrease the amount of nutrition given through tube feedings. Eventually, some children will take all of their food by mouth. Others will continue to get all or part of their nutrition by tube.

If children are eating by mouth, our dieticians check for nutritional adequacy by watching their weight. Our specialists will keep a food record to determine if your child is eating enough to reach his or her daily nutrition goals.

Our staff also help children who have difficulty with the process of eating. Family members or caregivers can assist as well. For example, if children have problems knowing how much food to eat or put in their mouths, the rehabilitation team and caregivers can watch them to make sure they are safe. If children have visual problems that keep them from seeing what's on one side of their plate, their place settings might be changed. Adaptive feeding equipment, such as special plates, bowls or utensils, is available as needed.

Maintaining a Healthy Weight

Children often lose weight right after a brain injury. Immediately after an injury, the body requires extra calories and protein to repair itself. A brain injury puts stress on a child's body, increasing the metabolic rate. An increased metabolic rate means that a child's body burns calories faster than usual. In addition, some children experience a loss of appetite due to depression or pain. During the initial recovery phase (up to eight weeks) children might need extra nutrition to maintain their weight or slow the rate of weight loss.

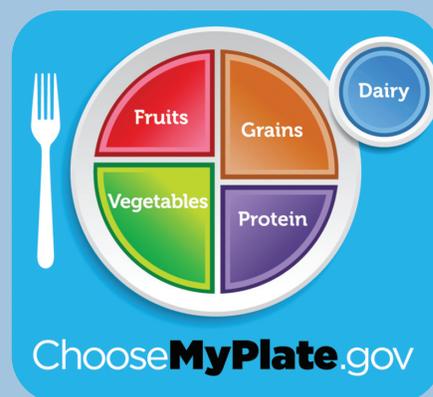
As a child's body adjusts to the injury, his or her caloric needs will stabilize or decrease. Most children are less active after a brain injury and need fewer calories to maintain their previous weight. Lack of activity might even lead to weight gain.

Your doctor or dietitian will set goals for the amount of fluid your child needs to drink each day. Water, milk, juice, sodas and other sports drinks contribute to daily fluid intake. However, it's important for your child to get at least half of the fluid directly from water. Digestion, urination, skin tone, blood pressure and all body processes require water to work properly.

How Can I Help Monitor My Child's Weight?

Being overweight can decrease a child's mobility, endurance and balance. That's why you should carefully monitor your child's weight.

Help your child eat healthy, well-balanced meals as outlined on the United States Department of Agriculture's food guide, My Plate.



- Monitor portion sizes and choose healthy snacks.
- Weigh your child once a week.
- If weight gain is a problem, contact your health care providers.
- Encourage your child to be physically active everyday.

A registered dietitian is available to answer your questions while your child is in the hospital. Your child also can see a dietitian by appointment in our outpatient clinic.

What's My Role?

We rely on parents for help with bowel and bladder management. Parents often know the signs their children exhibit right before they need to use the bathroom. For example, you might recognize by your child's facial expression or know that right after eating, your child will have a bowel movement.

We encourage you to watch for cues that your child needs to use the bathroom.

Bowel and Bladder Management

After a brain injury, some children are unable to control their bowel and bladder functions. Some children aren't aware or alert enough to recognize that they need to use the bathroom. Other children can't control their sphincters (the muscles that control the release of stool and urine). Some children are unable to communicate when they need to use the bathroom, or they can't move quickly enough to get onto the toilet. As the brain heals, some children might recover some or all of their bowel and bladder control. Others will continue to need various levels of support.

In the intensive care unit, your child might have needed a urinary catheter to drain urine from the bladder. The catheter will usually be removed before your child comes to the rehabilitation unit. If your child has had internal damage to the urinary tract, however, we might leave the catheter in place. Children who are unable to communicate that they need to use the bathroom might wear a brief (a type of diaper). Children who have limited mobility might need to use a bedside commode (portable toilet).

Beginning a Bowel Management Program

Because children are inactive when they're in intensive care, constipation can be a problem. Some children might need changes in diets, enemas or medicines to keep their bowels moving regularly. Other children need a bowel program.

If a child is on a bowel program, they are given suppositories or mini enemas at the same time every day (or every other day). The child then sits on a commode or toilet. If a child regains the ability to communicate and is able to maintain bowel continence (control), the bowel program might be stopped.

Bladder Retraining

It takes longer for children to achieve bladder continence (control) than bowel control. Bladder retraining is a bit like toilet training. It's a three-step process:

- Children first need to show awareness that they are wet.
- They need to show awareness that they need to use the bathroom.
- They need to be put on a toilet or commode at regular intervals so we catch them when they need to urinate. (This is known as timed voiding.)

During retraining, children continue to wear briefs. As children become more successful at urinating in the toilet or commode, we lengthen the interval between toileting times.

Once children learn to manage bowel and bladder functions and are continent, they can resume wearing underwear. If applicable, your nurse will provide you with information about how to do bowel management and bladder retraining at home.

Managing Pain

We'll give medicine to help keep your child comfortable and might use other pain-control methods, such as complementary therapies or distraction. We offer music, interactions with our staff and deep breathing. In addition, we offer aromatherapy, which might lessen any anxiety, discomfort or nausea.

You should tell your health care providers if your child has allergies or side effects to certain medicines. Also, tell us what pain-relief methods and medicines have worked well for your child in the past. Ask your nurse to teach you about other ways to manage pain, such as:

- Ice/heat
- Music
- Distraction (such as videos or games)
- Backrubs or massage
- Changing your child's position
- Deep breathing and relaxing

How Can I Help Manage My Child's Pain?

Tell us what pain-relief methods and medicines have worked well for your child in the past.

What's My Role?

We'll rely on you to help keep your child's trach tube clean and clear. At first, a nurse or respiratory therapist will do the suctioning. Then family members will be taught how to do this. You'll know if your child needs suctioning if you hear the "gurgly" sound of secretions or if your child is having trouble breathing.

Respiratory Care

Your body needs a constant supply of oxygen to be healthy. A brain injury can disrupt or alter the supply by interrupting your breathing patterns. The respiratory system is made up of lungs and airway passages. Your nose helps filter dust and dirt from the air you breathe. It also acts like a heated humidifier. The trachea, also known as the windpipe, leads from the throat to the lungs.

Children with severe brain injury or physical injuries in addition to their brain injury might need help with breathing or with coughing up secretions (phlegm).

Tracheostomy (trach)

If a child has a lot of lung secretions or is on a ventilator for a long time the child might need a trach. A trach tube will be placed in the child's windpipe (trachea). This allows health care providers and caregivers to frequently suction a child's lungs until he or she can cough up secretions (phlegm).

Suctioning

Children who have tracheostomies sometimes need suctioning to remove secretions from their airways. A trach tube bypasses the parts of the body that warm, clean and moisten the air you breathe. The body reacts to this change by producing more secretions. A sterile suction catheter is inserted down the trach tube to remove the secretions that can't be removed by coughing.

Decannulation

The removal of a tracheostomy tube is called decannulation. The trach tube will be removed and a bandage is placed over the opening on your child's neck. This should heal in a few days.

Managing Spasticity

Brain injuries can cause spasticity. Spasticity is the presence of overly tight muscles caused by a lack of normal communication between the brain and spinal cord. When messages are communicated properly the brain can signal the muscles to relax. This gives a child appropriate muscle tone—enough strength and flexibility to maintain posture and perform quick, smooth movements. If the brain's signals aren't correctly sent, the muscles become spastic and put up unusually high resistance to forces that come from outside the body.

While there's no known cure for spasticity, your child's health care providers might order medicines to help manage spasticity. Injected medicines, combined with physical and occupational therapy and casting, can sometimes limit muscle shortening that forms after a brain injury. Medicines might also help relax muscles to improve your child's ability to move and to be comfortably positioned.

How Do We Plan for A Long-Term Recovery Process?

When a child has a serious medical condition, our neuro-palliative care specialists help patients and their families make care decisions. Our specialists can suggest ways to manage your child's pain and other physical and emotional symptoms that are often a part of a long-term recovery process.

The neuropalliative care specialists can help you develop care goals, such as comfort and enjoyment of life, which can help guide your medical care decisions.

“Some days it’s very hard to believe that things will get better, but they will!”

– A Gillette Parent

Medical Issues

Some children might have some of the following medical issues after a brain injury:

Sleep Disturbances

Children with brain injuries are likely to have sleep disturbances such as hypersomnia (daytime sleepiness), fatigue (temporary loss of strength and energy), difficulty falling asleep or difficulty staying asleep. If your child is experiencing a sleep disorder, it might mean that he or she is experiencing a worsening of other symptoms such as:

- Pain
- Cognitive deficits
- Fatigue
- Irritability

If sleep deprivation is affecting your child’s recovery, we’ll work with you to treat your child’s sleep disorder.

Post-Traumatic Seizures

Approximately 10 percent of people who experience severe brain injuries will develop seizures. In about half of these, seizures are limited to a few days after the injury. Other people, however, continue to have occasional seizures weeks after their injuries. Sometimes seizures develop years later. Health care providers believe that scarring in the brain might cause delayed onset of seizures. If children have seizures in the first two weeks after an injury, it does not necessarily mean that they will continue to have seizures.

If children are taking medicines to prevent seizures when they arrive at Gillette, we might stop the medicines for a period of time. If your child needs to remain on seizure medicines, a pediatric neurologist will monitor the effects and be part of your child’s care.

Central Autonomic Dysfunction

In the early stages of rehabilitation, children might experience severe increases in blood pressure, temperature, heart rate, sweating and body stiffening (called central autonomic dysfunction). These symptoms appear when the parts of the brain that control these functions are irritated or stimulated. We use medicines to try to control these from occurring. Sometimes central autonomic dysfunction is resistant to treatment. Because we begin with low doses of medicine and then gradually increase the amounts, medicines might not be immediately effective.

Planning To Go Home

What Can I Do?

During family conferences and when you meet with your child's health care providers:

- Ask what therapy services your child will need after you go home.
- Find out if your child will need special medical services at home.
- Ask about special training your child's caregivers might need.
- Ask about your child's equipment needs.
- Discuss mobility, daily living, school, work, recreation and transportation.

Our goal is to have children return to their homes, schools and communities as soon as possible. That's why we focus on discharge planning at the beginning of the hospital stay. We'll help your family find community resources and information about:

- Specialized equipment
- Home modifications
- Financial resources
- Community therapy
- Personal care assistants
- Home health care services

The rehabilitation team evaluates your child just before discharge so that you have a realistic picture of your child's outpatient needs. If necessary, we'll help you select equipment for use at home.

After Discharge

You will receive a copy of each health care providers discharge planning summary before leaving the hospital. Your discharge planning summaries will also be mailed to you. These contain a summary of your child's progress during his or her hospital stay. They also include recommendations of what to continue working on in outpatient therapies.

We will continue to help you after discharge. Gillette's Telehealth nurses are available 24 hours a day to answer questions, call 651-229-3890. If needed, our nurses can contact a pediatric rehabilitation medicine doctor. Your child will likely have follow-up evaluations with doctors, therapists, and other staff.

When looking for and selecting therapy services, talk with your child's doctor, therapists and social worker. Therapy services are available through hospitals, rehabilitation centers and private therapy providers. In addition, you might find therapy providers in the phone listings or in service directories provided by therapists or community organizations.

Choosing Community Services

Once you know what services your child will need and how they'll be paid for, you can choose a health care provider. Selecting a provider before your child is discharged helps ensure that therapy services are uninterrupted.

You might have several providers from which to choose.

When selecting a provider:

- Consider the health care provider's experience working with children who have similar conditions.
- Interview the provider and ask for references from other families.
- Visit the provider and, if possible, observe a therapy session.

Some therapies are available through public schools. However, public school therapy must relate to the child's educational needs. After discharge, your child might have therapy or rehabilitation needs that schools can't provide. If you have questions or concerns, feel free to discuss them with Gillette staff.

Planning for Life Outside the Hospital

We'll hold conferences with the entire team—occupational therapy, physical therapy, speech therapy, child life, school services, therapeutic recreation, psychology, physicians, nurses and rehabilitation coordinators—every two or three weeks during the rehabilitation stay. In these conferences, we review your child's progress toward goals and objectives and the overall care plan. We'll also discuss the following topics during these conferences:

- Therapy services your child will need after discharge
- Length of time your child might be in the hospital
- What you will need once your child returns home, such as a ramp, bathroom modifications, accessible transportation, etc.
- Changes in your child's schooling

Early planning helps ease the transition from the hospital to the community and might even shorten your child's hospital stay.

We hold a discharge conference within the last two weeks of your child's stay to review overall progress on the rehabilitation care plan and make final discharge plans. We'll talk about what your child will need once your child returns to your home and community.

Before discharge, whenever possible, we might provide your child with a therapeutic pass to go home for a day visit or for an overnight, if insurance allows. After the visit, we'll discuss the experience with your family. Your feedback will help us understand what's needed to keep your child safe at home and school.

What Should I Know About Paying for Services?

Insurance companies, health maintenance organizations (HMOs) and other third-party payers, including Medical Assistance, pay for a number of services. However, some payers limit coverage to certain therapists or locations (for example, hospital outpatient services).

Many require prior authorization. Find out what your insurance covers as soon as possible. Doing so will help us develop a plan for therapy before your child is discharged.

How Can We Prepare for My Child to Return to the Classroom?

Before your child returns to school, a child life specialist might visit your child's classroom. We'll obtain your permission before the visit. Typically, the visit occurs without the child being present. That allows us to have a discussion that's free of embarrassment or self-consciousness for our patients and their classmates. Your child might, however, suggest information for the child life specialist to share with the class.

Planning to Return to School

Returning to school can be challenging for children who have had a brain injury. Look at the *Return to School after a Traumatic Brain Injury* brochure included in this guide to learn about how you can plan for your child's transition back to the classroom.

As your child prepares to return to school, the rehabilitation team completes assessments that will help you and the school district decide on an educational program that best meets your child's needs. We'll assess daily school activities to determine what your child can do independently and where help might be needed.

With your approval, we'll invite representatives from your child's school district to attend the discharge conference. Some school districts might want to observe your child during therapies in the hospital. We'll share information about your child's strengths and needs and help prepare for your child's return to school.

Individuals With Disabilities Act (IDEA)

If children's educational needs change after a brain injury, they might be eligible to receive accommodations and modifications under Section 504 of the federal law, Individuals with Disabilities Education Act (IDEA) or special-education services with an Individual Education Plan (IEP).

In addition, all school districts are required to provide children with access to a staff member who is knowledgeable about and familiar with the needs of people who have brain injuries. This person will be an important member of your child's school transition team who might provide support and guidance throughout your child's school years.

Support for Families

After a brain injury, children and families often need support adjusting to difficult life changes and coping with complex emotions. That's why we offer a wide range of support services in addition to rehabilitation and medical care. Even after discharge, Gillette's Child and Family Services staff can speak with you about your concerns.

Learning to live with a brain injury can be difficult and it may take a long time for the individual and family to adjust. The rehabilitation team can provide your family and/or friends with information regarding counseling, resources, and/or support organizations.

Here are some resources we suggest:

Brain Injury Association of America

800-444-6443 (toll-free)

www.biausa.org

The organization provides medical information about brain injuries and national resources for people who have experienced brain injuries and for their families.

Brain Injury Association of Minnesota

800-669-6442 (toll-free)

www.braininjurymn.org

The organization provides local resources for people who have experienced brain injuries and for their families.

Courage Center

763-520-0312

888-846-8253

ServiceCoordinator@CourageCenter.org

www.couragecenter.org

The center specializes in rehabilitation services for people with brain injuries, spinal cord injuries, stroke, chronic pain, autism or disabilities experienced since birth.

Epilepsy Foundation of Minnesota

800-779-0777 (toll-free)

www.efmn.org

The organization provides effective, accessible general resources to people with epilepsy and families affected by epilepsy.

Health Resources and Education

Located on the fourth floor of Gillette, Health Resources and Education can:

- Provide information about disabilities
- Offer a library of print and video titles
- Give you maps and general information about the Twin Cities
- Help you set up a CaringBridge web site to communicate with family and friends during your hospital stay
- Offer computers with internet access for you to do a health information search or update your CaringBridge site

**“Befriend other families.
Get to know other kids
on your unit.”**

– A Gillette Parent

Family Voices of Minnesota

www.familyvoicesofminnesota.org

The organization helps families to navigate health care systems and involves families in program and policy development, implementation and evaluation. As a member of the Parent to Parent USA Alliance, the organization also connects families through one-to-one matches to help provide support and information.

Minnesota Department of Education

651-582-8226

Barb Sisco, state low incidence specialist

barbara.sisco@state.mn.us

www.education.state.mn.us

The state agency provides general information, standards and resources regarding public school education, including special education.

Minnesota Department of Employment and Economic Development

651-297-1291

888-438-5627

www.deed.state.mn.us

The department provides resources for workers and postsecondary students with traumatic brain injuries.

Minnesota Department of Human Services

651-431-2000

www.dhs.state.mn.us

The department helps people meet their basic needs by providing or administering health care coverage, economic assistance, and a variety of services for children, people with disabilities and older Minnesotans.

Minnesota Low Incidence Projects

612-638-1532

Deb Williamson, statewide traumatic brain injury specialist

deb.williamson@metroecs.org

www.mnlowincidenceprojects.org

The program provides specialized support and technical assistance to school districts across the state, assisting their efforts in serving students in the low incidence areas of special education, including traumatic brain injury.

PACER Center

800-537-2237

www.pacer.org

PACER (Parent Advocacy Coalition for Educational Rights) Center provides information, resources and support to parents of children with disabilities. Advocates can help families understand and navigate the health and education systems.

The Sarah Jane Brain Project

www.thebrainproject.org

The Sarah Jane Brain Project creates a model system of care for children and young adults who are suffering from acquired brain injuries. The goal of the organization is to learn more about the brain.

United States Department of Education

800-872-5327

www.ed.gov

The department provides information about special education in the United States, including information about traumatic brain injuries.

Who Can We Call with Questions After We Return Home?

Call Gillette Telehealth Nursing at **651-229-3890** with any concerns. We'll take your call 24 hours a day.

Our Mission

Gillette Children's Specialty Healthcare provides specialized health care for people who have short-term or long-term disabilities that began during childhood. We help children, adults and their families improve their health, achieve greater well-being and enjoy life.



St. Paul (Main) Campus
200 University Ave. E.
St. Paul, MN 55101
651-291-2848
800-719-4040 (toll-free)

Brainerd Lakes Clinic
15860 Audubon Way
Baxter, MN 56401
218-824-5001
800-578-4266 (toll-free)

Burnsville Clinic
305 E. Nicollet Blvd.
Burnsville, MN 55337
952-223-3400
866-881-7386 (toll-free)

Duluth Clinic
Lakewalk Center
1420 London Rd.
Duluth, MN 55805
218-728-6160
800-903-7111 (toll-free)

Maple Grove Clinic
9550 Upland Ln. N.
Maple Grove, MN 55369
763-496-6000
888-218-0642 (toll-free)

Minnetonka Clinic
6060 Clearwater Dr.
Minnetonka, MN 55343
952-936-0977
800-277-1250 (toll-free)

Willmar Clinic
Lakeland Health Center
502 2nd St. S.W.
Willmar, MN 56201
651-634-1938
800-578-4266 (toll-free)

Mobile Outreach Clinic
For locations and schedules:
651-634-1938
800-578-4266 (toll-free)
www.gillettechildrens.org



St. Paul - Phalen Clinic
435 Phalen Blvd.
St. Paul, MN 55130
651-636-9443
800-578-4266 (toll-free)

www.gillettechildrens.org

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