GAYLORD
BRAIN INJURY EDUCATION
MANUAL
AN EDUCATIONAL GUIDE FOR PATIENTS & CAREGIVERS

with excerpts from
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Introduction

The mission of Gaylord Specialty Healthcare is to preserve and enhance a person’s health and function. Our hospital values, which guide all of our actions, are clinical excellence, compassion, integrity, respect, and accountability. Our vision is to promote patient functionality through the best clinical services, most advanced and effective treatment protocols, and documented outcomes for our patients.

The Brain Injury Rehabilitation Program is one of the largest programs at Gaylord Specialty Healthcare. Rehabilitation after a brain injury is a shared effort. The brain injury survivor and their support system work together with the assistance of an interdisciplinary group of Gaylord professionals. This team approach is essential to maximize the physical, cognitive, linguistic, psychological, emotional, spiritual, and social recovery. This education manual is dedicated to all our past, present, and future brain injury survivors, their families, and support system - the true core of every rehabilitation team.

SECTION 1

What is a Brain Injury?

Over two million people are hospitalized in an average year with a brain injury. Currently, 5.3 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result a traumatic brain injury. Many of those people are injured in falls or car accidents. It is important to note that one does not have to be traveling at a high rate of speed to incur a brain injury, nor does one have to hit their head on an object (steering wheel or the ground) to injure the brain. Even at moderate rates of speed, i.e. falls, traumatic brain injuries can and do occur. Three separate processes can injure the brain:

bruising (bleeding), tearing, and swelling. Brain injuries have a range of severity and symptoms from concussion to severe traumatic brain injury.

Bruising (Bleeding)

When a person is traveling at a certain speed, i.e. 45 miles per hour in a car, or accelerating toward the ground in a fall, then comes to a sudden stop in an accident or on the ground, the person’s brain goes from 45 miles per hour to zero in an instant. The soft tissue of the brain is propelled against the hard bone of the skull. The brain tissue is “compressed” against the skull and blood vessels may tear. When blood vessels tear, they release blood into areas of the brain in an uncontrolled manner.

This is concerning from a medical perspective, as there is no room for this extra blood. The skull, being hard, does not expand. As a result, the blood begins to press on the softer, more delicate brain tissue. With large amounts of bleeding in the brain, the pressure will make critical areas of the brain stop working. Areas that control breathing or heart rate could be affected, and a life or death situation could develop within hours of the injury.
There is also a rebound effect that the brain goes through during a sudden stop. The brain is thrown against the front part of the skull, causing bruising, but then the brain rebounds off the front of the skull and hits the back of the skull. This bouncing of the brain, first against the front of the skull and then against the back of the skull, can produce bruises in different parts of the brain. Thus, people can have bruising not only where their foreheads hit first in their accident, but in other areas of the brain as well. Medical professionals call this a “coup contra coup” injury.

**Tearing**
During this forward and backward motion that occurs during an accident, the brain can be torn. Tearing in the brain “cuts” the wires that make the brain work. This happens on a microscopic level (the brain has about 100 billion of these “wires” also known as neurons and axons). This tearing may not show up on some typical medical tests.

**Swelling**
When there is tearing and bruising, swelling will also occur. Swelling is the body’s reaction to injury, (think about spraining an ankle). In a brain injury, there is no extra room for this swelling, because of the hard skull, and the pressure begins to build. This pressure compresses the tissue and can damage important structures in the brain. The brain is highly reliant on oxygen, which is transported to the brain through the bloodstream. If the blood supply to the brain is interrupted for just 10 seconds, one can lose consciousness. After 2-3 minutes, permanent damage to the brain tissue will occur. If there is too much pressure, doctors will create a type of “relief valve” (intra-cranial pressure monitor [ICP] or a craniotomy) to relieve the excess pressure on the brain. This involves removing a piece of the skull bone.

**Open Versus Closed Head Injury**
A head injury can be described as either open or closed. In an open head injury the bones of the skull are fractured; in a closed head injury the skull bones remain intact but there is still injury to the brain. Either type of injury can cause serious complications. One would assume that the open skull fracture would be worse, but this is not always the case, as the closed head injury can allow pressure to build inside the skull.

**How the Brain Works**
One must understand the brain in order to truly understand how it can malfunction. The brain is the control center for the entire body. It controls how one moves, thinks, feels, and behaves. The brain is part of the central nervous system and is protected by the hard bones of the skull. The brain weighs only three pounds but is estimated to have about 100 billion cells. Most cells in the body divide and reproduce throughout our lives. The neurons of the brain are different. They are created only during fetal development and for a few months after birth. After that, no new brain cells will form. The existing cells may grow in size until about the age of eighteen. These cells are designed to last a lifetime.

Often times the brain is thought of as a big computer, but it is more similar to millions of little computers all working together. Perhaps a better example of a brain is an orchestra. In an orchestra, there are different instrument sections. There is a drum section, a string section, a woodwind section, and so on. Each has its own job to do and must work closely with the other sections. When the conductor raises a baton, all the members of the orchestra begin playing at the same time, on the same note. If the drum section doesn’t play as well as the rest of the orchestra, the overall sound of the music seems “off” or sounds poor. This is similar to how the brain works. It demonstrates how many parts work in concert with one another and how one part being slightly “off” affects the whole; this is descriptive of a brain injury.

**Information In and Out of the Brain**
The brain receives information such as temperature, pain, and movement from the spinal cord which enters at the base of the brain. The spinal cord is like a thick phone cable with thousands of phone lines within carrying information up into the center of the brain and then branching out over its surface. If the spinal cord is cut, a person would be unable feel anything in the body because those messages can’t reach the brain. Information also exits the brain through the spinal cord, carrying messages to control the motion of various body parts. Likewise if the spinal cord was cut, the brain cannot send the messages to control the body and a person is paralyzed. Vision and hearing are not transmitted through the spinal cord, but go directly into the brain. Thus, if someone has a complete spinal cord injury, they may be paralyzed (unable to move or feel their arms and legs), but are able to see and hear.
Information enters from the spinal cord and comes up to the middle of the brain. It branches out like a tree and goes to the surface of the brain. The surface of the brain is gray due to the color of the cell bodies (that’s why it’s called the gray matter). The wires, or axons, going to the surface have a coating on them that is white in color (and is called white matter).

The Healthy Brain: Two Brains & 4 Lobes—Left and Right Hemispheres
The brain is divided in half, a right and left hemisphere. The right hemisphere is important in visual activities and plays a role in the organization of vast amounts of information. For example, it takes visual information, puts it together, and says “I recognize that—that’s a chair,” or “that’s a house.” It also plays a role in our self-awareness, visual memory, perception, and creativity. In addition, the right hemisphere controls movement of the left side of the body.

The left hemisphere analyzes the information collected by the right hemisphere and, then interprets the information and applies language to it. The right hemisphere “sees” a house, but the left hemisphere says, “Oh yeah, I know who’s house that is—it’s Uncle Bob’s house.”

The left hemisphere also controls speaking, verbal memory, sequencing, logic, and the ability to understand language. The left hemisphere also controls the movement of the right side of the body. A person with an injury to the left side of the brain may be unable to move their right arm and have significant difficulty speaking. Someone with an injury to the right side of the brain may be unable to move their left arm and have very limited ability to recognize their own deficits, also referred to as poor insight.

The left and right hemispheres of the brain are divided into four lobes: frontal, occipital, parietal, and temporal. The lobes on the right side have different functions than the lobes on the left side. The frontal lobe is the center of thinking and problem solving. The occipital lobe translates visual signals received from the eyes. The parietal lobe processes sensory information such as touch and body temperature. Smell, touch, and processing sounds are the job of the temporal lobe.

Vision—How We See Things
Information from our eyes goes to areas at the back of the brain, the occipital lobe. Each hemisphere processes half the visual information. The nerves that bring information to the brain cross. Thus, visual information that is seen on the left gets processed by the right hemisphere, and visual information that is seen on the right gets processed by the left hemisphere.

Hearing and Language
The left temporal lobe is responsible for understanding language that is being heard, recognizing words, or putting words or pictures into categories. Because humans tend to think and express themselves in terms of language, the left temporal lobe is critical for day-to-day functioning.

The right temporal lobe is responsible for processing musical information, identifying noises, localizing sound, communication without words, memory, and personality. If this area is damaged, it may be difficult to appreciate music, recognize a person, or stop talking.

Sensation
The parietal lobe receives information about sensation in a very narrow strip that goes from near the top of the head down along the middle of the brain to near where the ears are located. It’s called the sensory cortex and is located in the parietal lobe. Tactile (touch) information from the left side of the body goes to the right brain, just like movement and vision.

Movement
The area of the brain that controls movement, called the motor strip or motor cortex, is located in the frontal lobe. This area is next to the sensory cortex. Since movement and feeling are closely related, both areas are located next to each other in the brain. It is not uncommon for people with a brain injury to lose both movement and feeling in parts of their body.
Remember that an injury to the left side of the brain may cause difficulty moving and feeling the right side of the body. Likewise, an injury to the right side of the brain can impact movement and sensation on the left side of the body.

**Planning, Organizing, and Controlling**
The biggest and most advanced part of the brain is the frontal lobe. It is located in the front of the brain, just behind the forehead. The frontal lobe is involved in planning. After a brain injury to the frontal lobe, an individual may seem to lack motivation and have difficulty doing tasks that require multiple steps (i.e., getting dressed or planning a meal). In reality, it is not necessarily poor motivation, just difficulty with planning.

The frontal lobe is also involved in organizing. Many activities require a specific order of steps. When the frontal lobe is injured, there is a breakdown in the ability to sequence and organize. A common example is when people are cooking and leave out a step in the sequence. They may forget to add an important ingredient or turn the stove off. When getting ready to take a shower, they may forget to get a towel or not rinse out the soap in their hair before turning off the water.

Additionally, the frontal lobe also plays a very important role in controlling emotions. Deep in the middle of the brain are areas that control emotions. They are the site of primitive emotions, such as hunger, aggression, and sexual drive. These areas send messages to other parts of the brain to “Do something.” For example, if a person is really angry at his boss, he may want to yell and quit his job. The frontal lobe steps in to “regulate” that emotion and help him to respond more appropriately. Individuals with an injury to the frontal lobe may have great difficulty controlling their emotions, responses, and actions. They sometimes have “no filter” and say things that may be considered inappropriate, immature, or offensive. In these cases, the frontal lobe failed to stop or turn off the emotional system.
Arousal

The centers for arousal, or wakefulness, are scattered throughout the brain in a complex network. Therefore, it stands to reason, any injury to the brain may cause some change with wakefulness and arousal. By definition, a severe traumatic brain injury results initially in coma. While in coma, a person is not connected or interacting with their environment AND no amount of stimulation can make them do so—trouble with being awake and aroused. This appears as the deepest of deep sleep. After a traumatic brain injury, coma can continue for hours, days or months. The duration can depend on the severity of brain injury, medications in use and/or other medical complications going on at the time.

As patients recover from their brain injuries, the depth and duration of coma also lessens. Unlike the movies or TV when people awake from coma spontaneously fresh and renewed, in actuality the process is much more subtle and less dramatic. Sometimes it can be hard for the layperson to even know that important changes may be happening before their eyes. Spontaneous eye opening, non-reflexive responses to the environment and purposeful vocalizations can be one or more of the early signs that coma has come to an end.

Recovery from a severe brain injury with a prolonged period of coma often results in gradual and inconsistent periods of wakefulness. Early on, the patient may or may not be verbal; they may or may not interact with their environment; and they may or may not show signs of restlessness or moving about the bed/pulling at tubes or themselves. Improvements with arousal can be slow and inconsistent, on an hour to hour, and day to day basis. None of these early changes are necessarily predictable of what is to come, but instead indicate early signs of brain recovery.

Physical Effects

After a brain injury, the nerve cells in the brain may no longer send information to each other the way they normally would. This is why people with a brain injury may have changes in their physical abilities. A brain injury can affect muscle strength, coordination, balance, mobility, tone, sensation, and vision.

Muscle Strength

Change in muscle strength as a result of a brain injury can range from slight and almost unnoticeable to complete absence of strength. Paresis is defined as muscle weakness. Based on the complex make-up of the brain, muscle weakness can present in different ways. Depending on the location of the injury, only one side of the body may be affected. This is called hemiparesis. For example, a brain injury to the right side of the brain may cause left sided hemiparesis. A brain injury can also cause weakness on both sides of the body; this would be termed quadriparesis.

Muscle Control

Sometimes after a brain injury, the control or coordination of the muscle is affected. A person may have difficulty coordinating movements in the right direction or with appropriate force for an activity. This can affect the ability to reach or grasp objects, decrease fine motor skills, and make moving and walking difficult.

A person with a brain injury may experience difficulty with muscle control. This is called apraxia. This is a problem with motor planning. For example, the hand may have the strength to grab and hold onto a fork, but the brain is unable to tell the hand and arm to move through the typical path to bring the hand to the mouth for feeding. It is an inability to make planned, controlled movements.

Muscle Tone

A brain injury can affect muscle tone, the tension present in a muscle at rest. An increase in muscle tone is termed spasticity; and, it may develop over time, even weeks or months after an injury. Spasticity is a condition in which some muscles are overactive, causing stiffness or tightness. This can be painful. Some symptoms that may be noticed include: difficulty relaxing muscles, muscle spasms, and difficulty moving certain joints. Spasticity may affect the arm and leg and can make movements and tasks like dressing and walking very difficult.

The doctor, nurse, physical therapist, and occupational therapist will all play a role in both the evaluation process and the proper treatment of spasticity, if indicated. The occupational and physical therapists may recommend positioning and/or splinting devices to improve the motion in the limbs, as well as, to improve comfort and mobility. The nurse will work with therapy to carryover proper positioning in bed for comfort and preventing skin breakdown. The doctor may recommend a trial of medications to treat the spasticity.
Balance
Balance is controlled by multiple systems in the body including vision, sensation, and muscular strength – all of which can be affected by an injury to the brain. Balance is often affected early after a brain injury and can improve with time and therapy. Balance difficulties can make it difficult to sit up, stand, walk or react to movement.

Someone with balance issues might show:
• Unsteadiness when walking
• Inability to walk or sit without assistance
• Falls
• Holding onto furniture, walls, or other objects when walking
• Reports of dizziness or nausea

Helpful Hints:
• Use assistive devices, such as walkers or canes appropriately
• Remove all tripping hazards such as clutter, throw rugs, etc.
• Family can work with the therapists to learn how to best assist the person with a brain injury when they are sitting or walking
• Falls are one of the leading causes of traumatic brain injuries. Providing or arranging supervision or assistance once the person with a brain injury is home is very important to prevent falls and another brain injury

Feeling/Sensation
Changes in feeling or sensation after a brain injury are not uncommon. Some brain injuries cause complete loss of feeling on one side of the body. This is usually in the same places as the loss of muscle strength. Sometimes there are odd feelings that involve one side of the body—this can be numbness or a sense of “pins and needles.” On a few occasions, there are strange feelings or sensations that cause sharp pain. (Again, the areas involved are usually the same places as those with muscle strength loss.)

Without feeling on one side of the body, there can be less awareness that part of the body exists, often called neglect. When this happens, a certain part of the body may no longer feel ‘owned’ or acknowledged by the person with the brain injury. In the most extreme conditions of this syndrome, a person’s arm or leg is thought to belong to someone else.

Vision/Perception
Vision and perception are commonly affected after a brain injury. Problems can be related to visual attention, diplopia (double vision), spatial or depth perception, or hemianopsia, which is a loss of part of the visual field.

Visual attention is the ability to focus on an object or activity for any length of time. A person with visual attention problems might have difficulty finding an object in the space around them. Double vision, or diplopia, can cause dizziness and impair depth perception. This can lead to nausea in some cases and/or limit a person’s ability to reach for an object accurately or move safely.

In other cases, judging spatial relationships can be difficult. A person may have difficulty with discriminating right versus left or trouble seeing how objects fit together, such as in a jigsaw puzzle. This can also affect everyday activities such as dressing. A person may try to put an arm through the head hole in a shirt and be unable to recognize their mistake. When a person has impaired sensation on one side of their body and poor visual attention, the brain might “neglect” or forget about that side. A person with a visual neglect may forget to shave half of their face, start reading in the middle of a line, or bump into walls on one side when walking.

Still, other visual deficits can be related to hemianopsia. Hemianopsia is also called a visual field cut and is similar to a blind spot. A person with hemianopsia is missing one half of their visual field; only half of the information the eyes are sending is recognized by the brain. A person with a field cut is often unaware they are not seeing the whole visual field.

Helpful Hint: Family and friends should sit on the brain injury survivor’s affected side to help increase awareness of their injured side

Cognitive Effects
Thinking
A brain injury can cause changes with thinking, also known as cognition. Some areas of cognitive function include orientation, attention, memory, reasoning/problem solving, and executive functioning. One, some, or all areas can be affected.
Orientation is the awareness of oneself and one’s surroundings in terms of four spheres: person, place, time, and reason. Initially, one of the main objectives is for individuals with a brain injury to know who they are, where they are, what happened to them, and the day/date.

Attention is the ability to focus on something and process it. It is critical to all areas of our thinking skills. After a brain injury, attention can change in several ways. First, a person may not be able to focus his/her attention and become easily distracted. Second, a person may not be able to focus on a task long enough to finish it. Finally, it may be hard for a person to alternate or divide attention between two or more things at once. Difficulties in attention may be mild to barely noticeable or severe enough to interfere with simple daily activities. It is not uncommon for a person with a severe brain injury to only be able to attend to a task for a few minutes at a time.

Think of information flowing like water in a pipe. If the brain cannot handle the flow of information, it gets overloaded. People with brain injuries frequently have to cope with situations where there is too much information. When overloaded, some people become irritable or develop headaches. In large groups, some people with brain injuries are unable to filter out one conversation from the next and become overloaded.

In the early stages of recovery, many people adapt their lifestyle. For example, some people choose to avoid large gatherings or noisy restaurants. Some may opt to go to quieter restaurants or choose activities that are not as noisy. Because one cannot always choose quiet situations, a brain injury survivor must feel comfortable to TAKE BREAKS! They can find a quiet place and take a nap for an hour. Someone with a brain injury might want to go for a walk with just one other person. People with a brain injury should inform their family members about this problem; they can try to help cope with this. Equally important, families should be aware of potentially overstimulating environments and help plan accordingly. Some people wear ear plugs (for a noisy work environment or going to a basketball game). Think about how overwhelming the airport or mall is the day before a holiday; a simple trip to a restaurant during dinner hour may feel the same magnitude after a brain injury. It is not always overload from sound; visual overload is also common. Typically, very bright lights will cause overload and may cause headaches—wearing sunglasses often helps.

Visual overload can also occur from having to process too much information. For some people, finding their favorite breakfast cereal in a grocery store aisle that has over 50 different cereals can cause the same overload.

Someone with impaired attention might show:
• Short attention span, sometimes only minutes in duration
• Easily distracted
• Difficulty in attending to one or more things at a time
• Inability to shift attention from one task or person to the next
• Difficulty completing tasks

Helpful Hints:
• Focus on one task at a time
• The brain injury survivor should have their attention focused before beginning a task or conversation
• It can be helpful for family and friends to spend time visiting in a quiet place
• It is easier for most individuals with a brain injury to have just a few visitors at a time rather than large groups
• It may be best to avoid the cafeteria during the busy lunch hour.
• Leave the television off and decrease visual stimulation in the room.

Many people who have had a traumatic brain injury complain of slowed speed of processing. This is when thinking and processing information is slower than before the injury. This problem can improve over time, but can add to confusion. Someone might:
• Take longer to answer questions
• Take longer to understand things that were easily understood before
• Take a longer time to react and respond

Helpful Hints:
• Slow down and simplify information
• Break complex tasks and activities down into smaller steps
• Allow extra time to respond to questions and to comprehend and learn new information
• Avoid situations that are overstimulating (i.e., noise, crowds)
• Encourage people to slow down and repeat information
Reasoning and problem solving skills are used every day. Reasoning is a person’s logic and interpretation of the surrounding environment. Problem solving skills are used to handle challenges that may be encountered throughout the day.

Executive functioning skills are a person’s ability to plan, problem solve, and self-monitor. Simply put, it refers to how someone will “think on their feet”. The hospital environment is very structured. While in the hospital, people with a brain injury usually have very few complex demands, so changes in executive functioning skills may initially go unnoticed. They are sometimes seen more subtly as personality changes. For example, someone who was quiet and conservative may become noticeably more talkative or make comments or use language that is out of their usual character. Some people complain that they used to be able to handle ten things at one time, but, now can only handle one or two.

As an example, secretaries often have to do multiple activities simultaneously. They have to type, answer phones, talk with customers, and do filing; all at the same time. At home, a person may cook dinner, watch television, and have a load of laundry going at the same time. If a person with a brain injury has problems organizing and sequencing, they may lose track of one or more tasks. They could be watching TV or doing the laundry, only to realize that the food is burning.

Helpful Hints:
• Use a “Modified To-Do List” (This is also discussed in the Memory section)
• Practice organization skills early in the day. Fatigue will make the ability to organize worse

Most people who have had a severe traumatic brain injury experience some confusion after their injury. Sometimes the confusion only lasts minutes. Other times, it can last days or even weeks. Keeping brain injury survivors safe, reminding him or her about what’s going on and offering reassurance are important during this stage of recovery. Someone who is confused may:

• Be disoriented (i.e., not sure where he or she is, time of day, what has happened)
• Stare blankly, as in a “fog”

Helpful Hints:
• Keep oriented. Put calendars, clocks, family pictures, and/or a sign indicating where the brain injury survivor is and what has happened, in his or her room.
• A list of health care team members and what each one does may also be helpful
• Use a notebook to plan for and log events. Have a family member refer to it for details of daily events
• Frequent reminders of the brain injury survivor of correct details of past or present events
• Limit changes and provide structure in a daily routine

Memory
Memory is the ability to learn, keep, and use information. Impaired memory is a common problem after a brain injury. There are different types of memory. Two of the more important types are visual and auditory. Visual memories are the things we see, such as a familiar place or where we’ve left our car. We also have memory for language, including things that we’ve heard or read.

Immediate memory is the ability to remember information that is briefly saved. It doesn’t last very long—perhaps only a few minutes. Loss of immediate memory does not occur in every brain injured person. The problem for most people with a brain injury, however, is with loss of short term memory.

Short term memory is stored for a few seconds to a few minutes. Short term memory is commonly affected by a brain injury, resulting in an inability to remember the date, the day of the week, who you were conversing with and what you were talking about.

There’s some variation in how people define short-term memory. Some define it as the ability to remember something after 30 seconds or up to 30 minutes. In the case of a person with a brain injury, their immediate memory may be good, yet, they may still have problems with short-term memory. Impaired short-term memory is a significant problem.
**Long term memory** is the ability to recall information after a day, two weeks, or ten years. For most people with a brain injury, their long-term memory tends to be good, especially for events prior to the injury. After the injury, they have a harder time making new long-term memories. This is directly related to loss of short-term memory because information isn’t stored long enough to make it to long-term memory.

**Amnesia** is the loss of memory that you once had. It’s as if someone has erased part of your past.

**Retrograde amnesia** means lost memories for events prior to the accident. For some people, retrograde amnesia can cover just a minute or even a few seconds. For other people, retrograde amnesia may affect longer periods of time. As people recover from their brain injuries, long-term memories tend to return. However, memories tend to return like pieces of a jigsaw puzzle; bits and pieces returning in random order.

**Anterograde amnesia** is loss of memory for events following the accident. This is a result of the brain injury. Complex systems in the injured brain are disrupted, creating a chemical imbalance in the brain. Patients who have had a long hospital stay, may only be able to recall the last portion of their stay. As brain chemistry normalizes and brain systems begin working, memory also begins to improve.

**Confabulation** is when a person with a brain injury makes up false memories. These memories could be about events that never happened or memories of actual events that the person modifies. The details of the memories have been either omitted or embellished so the memory is substantially different than the actual occurrence. Sometimes these memories are very detailed and the person honestly believes the events happened.

There are two types of memory deficits, the storage of information and the retrieval of information. Information from short-term memory is stored into long-term memory; but, if the short-term memory does not work properly, the brain cannot process the information and store it in the right place. The use of compensatory strategies can help.

Most people use memory strategies on a daily basis, even people who have not had a brain injury. For instance, using a “To Do” list or reminder notes to “jog our memory” and help us complete tasks in the future. The second type of memory problem is retrieval of information. In this instance, information is stored in the brain but the brain is unable to find it. Eventually, the information may come, but not at a time when you need it.

**What Can I Do To Improve My Memory?**
There are no guarantees that memory will return 100%, but therapy can help to improve memory in two ways. The first is restoration. There are exercises and drills specifically designed to improve memory and working on them consistently can help restore previous abilities.

Compensation is the use of internal and external strategies to substitute for lost functions. Examples of external strategies include setting an alarm clock or timer, writing lists, placing medications into a pill organizer, using a daily planner, or utilizing the calendar feature on a smart phone. All of us have probably used internal strategies without realizing they are strategies, including repeating information, visualizing, or making associations to help hold onto small amounts of information.

Finally, memory can be affected by many things, even for people without a head injury. However for a person with a brain injury, the effects are multiplied. Fatigue, loss of sleep, strong emotions, and even certain medications (i.e. pain killers) are some examples of factors that can impact memory.

**Headaches**

Headaches following a traumatic brain injury are a common occurrence. Headaches can happen regardless of the severity of brain injury or whether or not skull or facial fractures are present. Statistics indicate that headaches can continue in 43% of persons with a brain injury for over three months, and up to 33% may continue to experience headaches beyond one year following their injury.

**Causes of Headaches**
There are many potential causes of headaches and often there is more than one factor involved at a time.
Mechanical sources include injury to bone, muscle, the lining of the brain (the meninges), or blood vessels.

The brain itself has no feeling; so, while the pain sensation may seem as if it is coming from the brain, it is really originating in everything around it. An acceleration or deceleration type injury can cause strain or stretching of the muscles and soft tissue connections from the neck to the base of the head and the head itself. Bone fractures can occur to the outside and/or inside parts of the skull. Fractures may also occur to the facial bones, including deeper parts such as the eye sockets and sinuses. Often there is little visible evidence of these fractures except for bruising or lacerations (cuts).

If surgery is performed to remove a piece of the skull to relieve swelling (craniectomy), pain or headache syndromes can result. Temporarily removing part of the skull, while lifesaving, can contribute to headaches that persist often until the bone plate is replaced (cranioplasty).

Injury to the blood vessels in the brain can result in vascular headaches. These headaches can produce pounding and throbbing sensations, similar to a migraine headache. Stress, movement, agitation, alone or in combination, can make these symptoms worse. Sometimes with this type of headache, light and sound can be very irritating.

Headache Management
Headache management can be difficult and complex; treatment strategies are often individualized. There is no “magic pill” that makes the pain go away immediately. Treatment requires environmental and pharmacologic options and often there is some trial and error involved.

Environmental management includes keeping stimuli to a minimum, including noise, light, activity, and stress. Rest periods are extremely important. While resting, “complex thinking activities” should be avoided. Uninterrupted restful sleep is encouraged. Adequate hydration is also very important, but can be challenging if there is also nausea. All of these factors must be fully addressed.

Heat, cold, and massage modalities can also play a large part in the relief of symptoms. Every bit is helpful, especially when there may be underlying soft tissue or muscle strain.

Pharmacologic or drug therapy is the other form of treatment. There are many classes of medication. The medication chosen will be specific to the type of injury and presenting symptoms.

Not every type of headache is well treated with narcotics. The most effective medication treatment plan usually includes a few different types of medications. This approach can attack the pain from different directions. Again, this may involve some trial and error.

Ideally, a good medication plan includes some medications that are scheduled, given at specific times, and others given as needed, for breakthrough pain. The key is to stay on top of the pain by receiving treatment before the headache becomes severe, using non-pharmacologic choices and avoiding overmedication. Too much medication or too much of the wrong medication can potentially contribute to headaches as well.

Constant re-evaluation of the treatment plan, modalities, symptoms, and clinical presentation are necessary. Modifications are often required and caution must be taken to be sure that new causes for the headache are not evolving. Sometimes new tests are required if symptoms change or do not improve as might be expected. Keeping a headache log with objective information can be helpful to track what helps and what may not. A journal is also helpful in tracking progress over several days, because often when constantly existing in pain, it’s difficult to see change even if it has occurred.

Seizures

A seizure is a sudden surge of electrical activity in the brain. Normally, the nerve cells communicate with each other with a balance of electrical and chemical interactions. After a brain injury, the nerve cells are affected by the damage. The actual structure of the brain tissue can change and a focus of irritable or unstable tissue may form. This leads to changes in the typically balanced electrical communication. Irritable tissue may cause overexcited electrical activity which becomes the source of seizure activity. The overexcited electrical activity can occur in one place or travel to other parts of the brain. Seizure activity will look different based on how the abnormal electrical impulses travel.
Not every person that has a brain injury has a seizure. However, it is the cell injury and bleeding that occurs immediately and/or the scar formation that happens later that will increase the risk of seizures. In fact, seizures occur in only five percent of people who have brain injuries. The highest risk for seizures is within the first two weeks after the injury.

Late seizures are those that occur six to nine months later, or more. These are caused by an irritable electrical area in the brain from structural injury or a scar.

A seizure can just happen or sometimes there can be a warning or aura (however, the warning time is not often very long). Some normal warning signs may include seeing lights or flashing, odd smells, ringing, or just a feeling that something is about to happen.

Seizures can look different; some types include:

**Simple seizures** usually just include movement or twitching of one body part only. It may start in a hand or foot. The movements can occur for several minutes and do not change much. There is no change in level of alertness. The symptoms are mostly annoying or uncomfortable. This kind of twitching or movement IS NOT the same as a spasm.

**Complex partial seizures** often look like staring episodes that go on for several minutes. Sometimes there is also lip smacking, grunting, or snorting. The person does not usually collapse or go weak; in fact, sometimes they may walk or move a body part. There is usually confusion after this seizure passes.

**Grand mal seizures** are what most people think about when considering seizure activity. These seizures always include change in level of consciousness. There is collapse and rhythmic movement and/or stiffening of one side of the body or the entire body. These episodes appear abruptly and violently and may last for several minutes. Gasping or change in skin color can occur if the airway or breathing is interrupted during the seizure.

After a seizure, there may be a sense of confusion, weakness, or extreme fatigue. Some people accidentally bite the inside of their mouth and/or tongue and/or lose bowel and bladder control. Some people recover quickly. Usually there is no memory of what happened, even if the episode was particularly violent.

A single seizure does not always involve treatment. Evaluation is required, but treatment is decided by type, frequency, history, and results of the evaluation. The evaluation includes review of medications, blood tests, imaging studies of the brain—including a CT scan, and sometimes an electroencephalogram (EEG). The EEG measures the electrical activity and looks for balance as compared to imbalance. An EEG is most helpful if there are signs of imbalance. A normal EEG after a seizure does not eliminate the possibility of a seizure disorder.

Treatment for potential seizures and seizure disorders come in two forms—short term and long term. Seizure prophylaxis, or use of AEDs (anti-epileptic drugs or anti-seizure medications), are prescribed for the first week after severe brain injury. There is clear scientific evidence that preventative treatment is indicated during this time. After this brief period of time, the evidence is not as clear. Seizure disorder treatment, again with AEDs, is necessary when a verified disorder has been determined. The same types of medicine(s) are used. It is always best to use as little and as few medications possible. If indicated, drug levels, blood counts and/or chemistries are tracked regularly by a medical professional.

Anti-epileptic drugs work by calming down the abnormal electrical activity caused by the damaged or irritable brain tissue. Of course, AEDs do not just work on the abnormal electrical activity but on all of the electrical activity in the brain. This can cause increased fatigue and slower speed with thinking or processing. With this being the case, overuse of AEDs is not recommended; risks versus benefits must be constantly weighed.

**Communication Effects**

Imagine saying “pass me the noon” when you mean to say “pass me the spoon.” Or, instead of using a similar sounding word, you say, “pass me the car” instead of “pass me the spoon.” Now imagine making these errors on a regular basis. This is an example of how communication skills can be affected after a brain injury. It can lead to frustration for the individual with the injury, as well as for the person who is attempting to communicate with him or her.

**Aphasia** is a language disorder affecting the ability to understand what is being heard or read, and/or the ability to express oneself through talking or writing. In the most severe case, a person may have difficulty expressing basic wants and needs.
In a less severe case, a person may have occasional difficulty recalling words and may have some difficulty understanding lengthy, complex conversations. Changes in communication skills vary from person to person. How severe the injury is and its location within the brain can affect these changes. Factors that play a role in communication problems include: behavior, memory, attention, other thinking skills, judgment, social skills, and self-awareness. Communication problems occur when the frontal and temporal lobes of the brain are injured.

Hearing or vision loss make it harder to communicate well. The speech language pathologists, neuropsychologists, and doctors will evaluate the specific communication areas that are affected. Feedback is important to help improve a person’s communication.

All areas of communication may be impacted following a brain injury, including:

• **Receptive Language**: auditory (listening) and reading comprehension
• **Expressive Language**: verbal and written expression
• **Speech Production**: oral motor movements and the clarity of speech

These communication skills are used constantly in everyday life. For example, understanding a conversation requires good auditory comprehension. Being able to read an article in the newspaper requires adequate reading comprehension. Stating wants and needs requires accurate verbal expression. Filling out a form requires adequate written expression. Producing speech that is easy to understand requires accurate speech production.

It is important to note that speech and language are different areas. Language has to do with finding the right words and using them appropriately, while speech has to do with how the words are said (i.e. slurred versus clear). A person may have clear speech, but may not be able to find the desired words to say. Additionally, auditory comprehension is different from the ability to hear. A person having difficulties with auditory comprehension may have good hearing, but cannot understand the words being said to him or her.

The following examples outline some common communication effects from a brain injury and helpful hints.

**Issues with Receptive Language: Auditory Comprehension**

What might be seen:
- Difficulty paying attention to what is said
- Misinterpreting what is said
- Being “off topic” compared to the rest of the people in the conversation

**Helpful Hints:**
- Get his or her attention before speaking
- Be clear and to the point
- Keep it simple
- Reduce distractions
- Periodically, stop and ask to restate what was heard
- Reduce the rate of speech and pause frequently to allow the person with a brain injury time to process and respond
- Avoid abrupt topic changes
- In group conversations, help set a slower pace of conversation

**Issues with Receptive Language: Reading Comprehension**

What might be seen:
- Problems understanding what is read
- Trouble stating the main idea or main point

**Helpful Hints:**
- Read with the person with a brain injury
- Review the reading material, using the 5W strategy – Who, What, Where, When, Why:
  - Who are the characters?
  - What happened to the characters in the book? What did they do about it?
  - Where did it happen?
  - When did it happen?
  - Why did it happen?
- Emphasize important information in the text
Issues with Expressive Language: Word Finding

What might be seen:
• Problems finding the right word to describe what he or she is trying to say

Helpful Hints:
• Give the person time to locate the word he or she is looking for
• If he or she still cannot locate the word after some time, guess at what he or she might mean
• Write it down or use gestures
• Encourage him or her to use another word that is close in meaning
• Be patient
• Suggest that he or she use many words (or a description) instead of using a single word (this is called circumlocution, a strategy speech language pathologists will often teach) i.e. if the a person cannot come up the word “belt” he may say “the thing that holds up pants”

Issues with Expressive Language: Conversational Difficulties

What might be seen:
• Unable to start or is slow to start conversations
• Long pauses
• Problems explaining what he or she means
• Not responding to another’s questions or comments
• Difficulties maintaining or changing topics
• Bringing up the same topic over and over again (called perseveration)

Helpful Hints:
• Ask a leading question such as, “What do you think about ....?“
• Ask open-ended questions (i.e., questions that cannot be answered with a “yes” or “no”), such as, “Tell me more about your day.”
• Give full attention
• Provide the person with time to organize his or her thoughts
• Use redirection, if necessary (e.g., “So what do you think about ....?”)
• Reinforce all efforts to start or contribute to a conversation

Issues with Expressive Language: Communication Style

• Politely interrupt and ask for a chance to speak
• Ask the person to be brief
• Develop a hand signal which indicates that they may be monopolizing the conversation
• Gently alert him or her to the fact that a topic change was too abrupt
• Use positive reinforcement for all attempts at listening rather than talking
• Encourage the person to let you know if he or she doesn’t understand what is being said

Issues with Expressive Language: Topic Selection Problems

What might be seen:
• Problems finding good topics for conversation
• Problems keeping up when topics change
• Abrupt introduction of a new topic
• Problems staying on topic

Helpful Hints:
• Pick topics that the person with a brain injury enjoys
• Clarify new topics as they come up
• Ask how his or her comment relates to the topic: (“How does the price of gas relate to what you ate for lunch?”)
• Tell the person with the brain injury when you are confused or getting lost in the conversation
• Gently but firmly alert the person with a brain injury if they are bringing up a topic that may be offensive to others

Issues with Expressive Language: Nonverbal Communication

What might be seen:
• Having a hard time understanding common nonverbal cues (i.e., facial expressions, hand gestures)
• Standing too close or too far from the speaker
• Making uncomfortable physical contact
• Using body language that doesn’t “match” what is being said
• Displaying facial expressions that don’t “match” what is being said
• Having poor eye contact
• Staring at others during conversation
Helpful Hints:
• Politely ask the person to stand closer or further away
• Explain the behavior is making you feel uncomfortable
• Tell the person with a brain injury that you are confused by the difference in body language and spoken message
• Give feedback on the right amount of eye contact to keep with another person
• Praise all improvements
• Decide on a signal to indicate problematic behavior

Issues with Expressive Language: Written Expression

What might be seen:
• Problems expressing thoughts in writing
• Problems getting started writing
• Writing the same words or phrase over and over (called perseveration)

Helpful Hints:
• Practice writing (i.e. write letters to friends or relatives)
• Make a list of openings (Dear, Hello, Hi, etc.) and closings (Thank you, Sincerely, Yours truly) and the reasons for selecting them
• Say words out loud before writing them
• Read what is written to make sure it makes sense

Issues with Speech Production: Clear Speech

What might be seen:
• Slurred speech
• Speaking too loudly or softly
• Speaking too rapidly

Helpful Hints:
• Tell your family member that you did not understand what he or she said
• Ask him or her to say it again more slowly
• Use a consistent cue or gesture to remind them if you did not understand (for example, cup your hand over your ear as a reminder to speak louder)
• Allow time for the person to express him or herself

Helpful Hints:
• Practically use the exercises prescribed by the speech-language pathologist, which, over time, will result in clearer speech
• Allow ample time for the person to express him or herself
• Encourage them to take their time when speaking
• Inform others about the diagnosis so they too allow the person time to express themselves

Issues with Speech Production: Apraxia

Apraxia is the inability to make planned controlled movements. A person with a brain injury may have one or more types of apraxia. The first type, verbal apraxia, causes trouble using words. A person may know what they want to say, but cannot correctly say it. Or, they may also “get stuck”, and say the same word or sound over and over (perseveration). A second type, oral apraxia, causes trouble with intentional movement of the tongue, lips, and jaw.

Helpful Hint
• Encourage and help the person to practice individual speech sounds and motor movements, as prescribed by the speech-therapist, on a daily basis

Swallowing

Dysphagia refers to difficulty swallowing food or liquids, which can occur after brain injury. The facial and throat muscles become weakened and are unable to move well, thus, creating problems with chewing and swallowing. Food and/or liquid may “go down the wrong way”. This is known as aspiration and can cause pneumonia.
Helpful Hint:
• Family and friends are asked to check with the staff before offering food or drink to a brain injured person to ensure their safety

Sleep Disorders

Sleep changes are very common after a brain injury and are usually worse in the first several weeks to months after the injury. These changes can include difficulty falling or staying asleep (insomnia), altered sleep schedules (awake at night, sleeping or napping during the day), a frequent need to nap, and sleeping too much or too little.

People with a brain injury can also have a fatigue disorder. This can be rather confusing, because one would think people with a fatigue disorder would have no difficulty sleeping. However, this is not always the case- both problems can be present.

Sleep is very important to the healing process, both physically and mentally. Lack of sleep can affect mood and cause irritability. It also can make memory problems worse. A good night’s sleep can also help the body relax, promoting muscle healing and recovery.

There are some steps to improve the ability to fall or stay asleep, which is generally referred to as “sleep hygiene.”

Helpful Hints:
• Limit daytime naps. If people sleep during the day, they won’t be tired at night. If the person with a brain injury is very tired, they can try resting without actually sleeping.
• Have exactly the same bedtime every night. This helps the body get into a routine.
• Avoid caffeine after the morning. This includes coffee, tea, soda, and energy drinks.
• Avoid exercising too close to bedtime. The body needs time to relax after a workout.
• Avoid drinking anything two hours prior to bedtime.
• Try to eat the last meal of the day about 4 hours before bedtime.
• Avoid using the bed for anything other than sleep and sex.

• Use room darkening shades and keep the room quiet and cool.
• Talk with a doctor about temporarily using sleep medication or other therapies to help establish a sleep schedule.
• Use a sleep diary if there is interrupted sleep. By keeping track of what is waking you up at night, you and your care team can better problem-solve how to avoid those distractions.

Many people with a traumatic brain injury do resume a more normal sleep routine similar to the one they had before the injury by using some or all of these techniques.

Fatigue

A nearly universal complaint with brain injury is fatigue. Although fatigue decreases over time, it can be a persistent problem. Many people recover from nearly all other deficits, only to have fatigue prevent them from returning to work full time (they return to work, but at a part-time level). Fatigue in those with brain injury can significantly alter their lifestyle.

Mental versus Physical Fatigue

There are two types of fatigue: physical fatigue and mental fatigue. “Physical” refers to doing some sort of physical labor such as mowing the lawn or working in a flower garden. After a head injury, physical fatigue may be troublesome. For example, if the person with a brain injury is relearning to walk, the amount of effort it requires to relearn to coordinate the muscles and build up strength is going to be substantial. For most, physical fatigue tends to go away after 6 months.

What surprises individuals with a brain injury is mental fatigue. For example, someone could spend all day in the yard pulling out weeds and not feel tired from it, but an hour of balancing the checkbook will leave them exhausted. This is mental fatigue and can go on for long periods of time. Another analogy would be owning a car that can only filled with half a tank of gas. Now it can only go half as far as it used to. When gas runs out- the engine stops. With mental fatigue, it’s as if the brain runs out of chemicals and just shuts down.

This occurs because the brain is rewiring and rerouting information. More time and energy is needed to send the same information as it did before. Individuals with a brain injury take much more effort to get the same answer.
The fatigue does typically get better over time though for most, it does not completely resolve. At first, people may work for just a few hours before feeling exhausted. Eventually, they work for several hours, but might become extremely tired in the evenings and need the weekend to recover. A cold, injury or other common unrelated illness may cause the fatigue disorder to briefly come back or exacerbate.

After a brain injury, it may be beneficial to restructure daily routines. Knowing that fatigue will affect memory, cognitively challenging tasks or new learning might be best if done in the morning. Scheduled naps or down times in the afternoon to rest, especially on busy days are important.

Exercise helps to improve one’s ability to think. Why? Even though the brain weighs less than 5% of the entire body, it uses 30% of the oxygen in the body, and probably the same amount of glucose (which is the energy that runs your body). Regular exercise helps the body use oxygen and glucose more efficiently and effectively, helping the brain. It is important to work with a doctor and therapists to learn about what exercises works best for each individual.

Diet is another important consideration. It is important to eat 3 good meals a day, and not rely on the sugar from a doughnut and the caffeine from a coffee to get a burst of energy. That energy does not last. A good diet of balanced nutrition will give a constant supply of energy to the brain.

For a person with a brain injury, it is wise to gradually increase their stamina. Going from not working to working 40 hours a week is stressful and most likely not a realistic approach. The brain needs time to build a tolerance to fatigue. A common approach to this problem is to gradually increase the amount of working hours (For return to work, starting part-time, perhaps with 1 to 3 hours, and increasing the hours as tolerated). The same can be said for returning to school.

Although some individuals can never return to full time work/school, there are other options to return to the community, such as volunteering. There are benefits to seeking activity outside the home, as this will offer the opportunity to feel useful, meet other people, and even build job skills. This will also help to decrease fatigue and will improve self-esteem.

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**Emotions**

People will accept that a brain injury can change thoughts and memories, but they may have a more difficult time understanding that it also changes emotions. It is very normal for people to be more emotional, agitated, angry, and depressed following a brain injury. Some of the emotional changes are discussed in more detail in Section 5.

One of the more common changes in emotion is anger. After a brain injury, anger takes on a different quality from “normal” anger. Minor events, such as spilling a cup of coffee, can cause the person to become very angry and the feeling can escalate quickly. Someone may have been a “hot-head” or an angry individual before their accident, but after the injury the anger can be more intense.

One helpful approach is the “Time-Out” option. It takes time for the emotional system to calm down. The more “Time-Out’s” are practiced, the more the person learns to control their feelings. Practice is important!

One problem with the “Time-Out” method is that people don’t realize that they are becoming increasingly angry until it’s too late. There are cues that anger is building, and it is important to learn the signs. It may be tightening in the jaw, it may be clenching in the hands, and it may be sweating more or breathing heavily. It depends on the person. Family members can help by gently suggesting a break or a walk or change of topic in order to mitigate building anger.

**Bowel and Bladder**

Problems related to bowel and bladder function are common but distressing for individuals with a brain injury. “Going to the bathroom” after suffering a brain injury may be complicated by urinary incontinence, urinary retention, constipation, and/or bowel incontinence. Urinary incontinence is being unable to control urination.

**Helpful Hints:**

- Plan regular and consistent trips to the bathroom to help train the bladder
- Drink plenty of fluids during the day and limit them in the evening
- Ask the physical therapist for exercises to help strengthen the muscles around the bladder
Urinary retention is having trouble urinating or not completely emptying the bladder. This condition can lead to bladder stones, reflux (reverse flow of urine back to the kidneys), or a urinary tract infection (UTI). Some symptoms of a UTI are foul smelling, cloudy urine, burning when urinating, fever and chills, cramps in the lower abdomen or side, pain in the lower back, frequent urination or feeling like one has to go to the bathroom even though the bladder is empty. If any of these symptoms are noted, a doctor should be seen promptly. A UTI needs immediate treatment.

Bowel incontinence is the inability to control the release of stool.

**Helpful Hint:**
- Develop a pattern. Opportunities to use the bathroom should be planned according to previous bowel habits

Constipation is being unable to have a regular bowel movement.

**Helpful Hints:**
- Use a sitting position that allows the person to lean forward
- Be active during the day to stimulate the process of bowel movement. Do not be sedentary
- Eat healthy foods with lots of fiber to reduce constipation
- Use a stool softener or bulk agent, enema, or oral laxative

Deep Vein Thrombosis

Deep vein thrombosis (DVT) is a serious risk after a brain injury. The lack of mobility after having a brain injury increases the risk of clot formation in the veins of the legs. Prevention of a DVT is critical. The best way to decrease the formation of blood clots is by early mobility, as well as the use of certain medications such as blood thinners (anticoagulants), if appropriate. Blood clots can be painful as well as life-threatening if a piece of the clot breaks off and travels to the brain or lungs. This is known as a pulmonary embolus. When a DVT occurs, treatment is dependent on the type of brain injury, how recent the brain injury occurred, and the ability to take blood thinning medications.

Respiratory Complications

Disturbances of the respiratory system and complications involving its function are possible after a brain injury. The nature of these disorders depends on the severity and site of neurological injury. Alterations in breathing control, respiratory mechanics, and breathing pattern are common and in severe cases can cause the need for mechanical ventilation. The injury to the brain can also lead to sleep disordered breathing such as central or obstructive sleep apnea. The person with a brain injury will be closely monitored for these potential disturbances and implementation of preventive measures can significantly improve outcomes.
**Transition to Rehab: Role of the Treating Team**

**Medical**

The physician is the team leader. This professional may be a specialist in Physical Medicine and Rehabilitation (Physiatrist) or in Internal Medicine. Since most patients have survived a severe and potential life threatening injury, continued management of medical complications beyond the acute care hospital is essential. Without medical stability, the person with a brain injury's full participation in a rehabilitation program would be impossible. The physician will assess many aspects of the ongoing health care needs of the person with a brain injury. Both pre-existing and new medical problems will be evaluated, monitored, and managed. The medical team may also include a physician’s assistant (PA) or an advanced practice registered nurse (APRN). Both play key roles in managing the brain injury survivor’s ongoing health care needs.

**Care Management**

The care manager coordinates health care services that an individual with a brain injury requires after discharge from the hospital. This is accomplished through a collaborative multi-disciplinary team approach. It is the responsibility of the care manager to provide education to the patient and their family, as well as to hospital staff regarding community resources, health insurance requirements, and payment/payer issues.

Discharge planning is initiated soon after admission. The care manager develops and revises individualized discharge plans as indicated by the team’s assessment, and the patient’s response to treatment. Many factors including the psychosocial, physical, educational, and cultural aspects are taken into consideration when developing this plan.

It is the role of the care manager to ensure that the plan of care promotes a safe and timely discharge, and to evaluate the overall plan for effectiveness. The care manager involves both the person with a brain injury and family in formulating goals for a safe discharge. The care manager is the link between the provider, the payer organizations, the physicians, and the community, as an individual with a brain injury transitions through the healthcare continuum of care.

**Food & Nutrition**

A consultation with a registered dietitian (RD) occurs shortly after the person with a brain injury is admitted. The dietitian will evaluate and monitor their nutritional status and provide guidance to the person, family, and team. Interventions may include education about healthy food choices to help manage chronic health conditions, assistance with managing poor appetite, or the addition of nutritional supplementation. If the patient has a feeding tube, the dietitian will assess and modify the tube feeding regimen, as needed. The dietitian works closely with the Speech-Language Pathologist (SLP) when a modified consistency diet is needed due to trouble swallowing. A representative from the Food & Nutrition department meets with inpatients daily for individual menu selections.

**Nursing**

A registered nurse is responsible for establishing a plan of care based on the needs of the patient. The ultimate goal of rehabilitation nursing care is to help patients regain control of and responsibility for their lives. It is important to remember that the focus is on the individual becoming more independent and less reliant on others as discharge approaches.

The nurse ensures that each person receives adequate nutrition and rest, administers medications, and performs treatments ordered by the physician. They address bowel and bladder training as needed. Nursing also monitors the individual to prevent or correct problems such as skin pressure areas, infection, wounds, and excess weight gain. This evaluation is ongoing during the hospital stay and is very important. Physical, cognitive, social, and emotional reactions are also observed and recorded. Rehabilitation nurses work closely with other team members. They help the person with a brain injury carry over the functional skills learned in other therapies and use these skills on the unit and in their room.

**Occupational Therapy**

The occupational therapist (OT) evaluates and treats areas which affect a person’s ability to care for his or herself. The role of the OT is to assist the person in achieving the highest level of independence possible in activities of daily living (ADL’s). This may include areas such as feeding, grooming, dressing, bathing, the ability to get to and from the bathroom, and preparing meals.
A person may need to relearn how to perform these activities and to compensate for visual, perceptual, and cognitive deficits. The OT also provides demonstrations and training to family members in the areas of self-care and mobility in preparation for a safe discharge. The OT may recommend adaptive equipment or modifications to the environment to assist the individual with a brain injury to perform task independently and safely. Recommendations for continued therapy services are made by the OT prior to discharge.

**Pastoral Care**

The chaplain is a person with specialized training, who has been authorized by a formal religious body to minister to the person with a brain injury, families, and staff in the healthcare setting. Their goal is to help facilitate a person’s use of their own faith, belief system, religious experience, or heritage during a crisis. The chaplain can provide religious resources, act as a helpful liaison with various religious bodies or communities, or assist the person with a brain injury and family to use faith and spiritual values to gain emotional support or spiritual strength.

**Physical Therapy**

The role of the physical therapist (PT) is to assist individuals with brain injuries to attain the highest level of mobility possible. The physical therapist will conduct an evaluation of movement in both legs comparing strength, sensation, tone, and coordination, which may often be impacted following a brain injury. The PT will also evaluate endurance, balance, as well as important mobility skills necessary for getting out of bed, walking, moving in or out of a wheelchair (transfers), and using stairs. After completion of the evaluation, an individualized treatment program is developed in consideration of both the person and family’s goals for rehabilitation. Family education and training is an essential component in recovery from a brain injury. Prior to discharge home, the PT might recommend that appropriate family member(s) attend treatment sessions for training to learn how to assist the patient with safe mobility in the home environment.

Recommendations for necessary assistive devices and continued therapy services are made by the PT prior to discharge.

**Helpful Hint:** Wearing loose and comfortable clothing, including sneakers and pants (no skirts), is recommended.

**Psychology/Social Work**

The psychologist/social worker is available to evaluate the person with a brain injury’s current function, including their emotions, personality, cognitive abilities, and behavior. In addition, the clinician will assess the adjustment to illness.

Psychological treatment may include the individual, family, and group therapy, to aid in adjustment issues and teaching coping skills to the individual and family members. Treatment includes collaboration with other care providers to ensure continuity of care. Individual and group sessions may be used to provide education and teach coping skills.

Once discharged from inpatient rehab; psychology practitioners/social workers may continue treatment in the outpatient rehabilitation setting. Collaboration with outpatient doctors, physical, occupational, and speech therapists, ensure continuity of care and confirm that the person’s needs are being met outside of the hospital setting. In addition, neuropsychological evaluations may be conducted, to further inform treatment; especially as individuals begin to resume premorbid life roles, such as school or employment or seek additional services in the home. Resource information is provided to help the person with a brain injury reconnect with their community and bolster their support network.

**Respiratory**

The respiratory therapist (RT) plays a key role in the management of a patient with a brain injury. The RT will initially assess for any and all respiratory needs including oxygen, medication therapies, airway clearance modalities, and airway interventions. The RT works together with the interdisciplinary team to best coordinate all aspects of the person with a brain injury’s care. The RT staff will also provide education on breathing interventions to maintain optimal respiratory function.
Speech-Language Pathology

If appropriate, the person with a brain injury is evaluated by a speech-language pathologist (SLP). The doctor will order an evaluation of swallowing, communication, and/or cognition. Following the evaluation(s), an individualized treatment plan is developed. Goals are set by the individual with a brain injury, family members, and therapist, to assist with return to the highest level of function possible.

Examples of speech therapy goals include: returning a patient to eating the least restrictive diet if he or she is currently not able to eat by mouth (NPO) or on a modified diet. Other goals may include using a speaking valve if a tracheostomy is in place, or remembering newly learned information. Treatment is given in individual speech therapy sessions and group therapy sessions if appropriate. Families are encouraged to participate in treatment sessions to promote implementation of all skills/strategies learned.

Therapeutic Recreation

Therapeutic Recreation (TR), also called Recreational Therapy, uses leisure and recreation programs to improve an individual’s quality of life and physical, cognitive, social, and emotional function. TR helps to improve abilities, enhance independence, and make participation in recreation possible. TR offers activities that address the physical, cognitive, social, emotional, and creative needs through engaging in activities of interest to each individual. Some examples of activities may include: board games, cards, Wii or video games, arts and crafts, iPad use, sports, and community re-integration.

Leisure education teaches or enhances recreation skills and attitudes that will be used throughout life. It can help the person to discover new and exciting activities through interest exploration and to re-familiarize them with their community. Leisure Education also helps an individual continue to participate in activities of interest through adaptive equipment.

Different Levels of Care for Brain Injury Rehabilitation

Individuals with a brain injury will be cared for by many people throughout the healthcare system. Recovery often follows a progression that is defined by the term “continuum of care.” This means that a person with a brain injury may transition from an acute care hospital through progressively less medically intense levels of care. The first step in the continuum is the acute care hospital. Patients are stabilized, medications are initiated, or their effect is maximized. Secondary complications from the brain injury and other medical problems are minimized.

Once someone is discharged from the acute care hospital, they go to the next level that is most appropriate for them.

That could be anywhere along the continuum of care based on each individual’s needs, from home with outpatient therapy to a long term acute care hospital (LTACH).

Most brain injured individuals discharge from acute care to a LTACH or an inpatient rehabilitation facility (IRF). An LTACH is an option for an individual with a brain injury who has specific, complex medical needs. Gaylord is an LTACH. We are able to care for individuals with brain injuries who also have medically complex problems and provide therapies that are equal to their needs (30 minutes to over 3 hours of therapy per day). The goal is to maximize function and health. The average length of stay at a LTACH level of care is 3 to 4 weeks based on each individual. An IRF is appropriate for a more medically stable population, for a shorter length of stay (14 days) and has strict rules on the amount of therapy (3 hours for everyone, despite their functional status).

Another option along the continuum is a sub-acute facility or a skilled nursing facility (SNF). These are institutions where people with a brain injury go if they have needs that cannot be met at home due to medical or physical needs. They do not require the complex medical care of a hospital but are not yet able to be home. These individuals may need to progress at a slower rate and are able to maximize their recovery prior to discharge. The typical length of stay is between 4 to 8 weeks. People can also transfer to an extended care facility as well, if home is not an option for discharge.
Following a stay at any facility, individuals with brain injuries can discharge home with home care (including skilled nursing visits, physical therapy, occupational therapy, and speech therapy as appropriate). Others may go directly to outpatient therapy.

Some people with brain injury begin their therapy at home to maximize their function there or because they are unable to get to outpatient therapy. After a typical 4 week course of therapy at home, people are often discharged to outpatient therapy. Some individuals with brain injury can discharge from a facility directly into outpatient therapy.

Outpatient therapy is typically more intensive than home care therapy. Outpatient therapy has the benefits of equipment and facilities not available in the home. Gaylord also has a large outpatient therapy department for individuals with a brain injury on the Wallingford campus.

**Family Members Role in the Hospital Setting**

For many family members, the initial hospital experience is frightening and confusing. One minute they are leading their lives when suddenly they are told to come to the hospital. The worst thoughts go through their heads and they most often are very afraid or confused. There are so many people going in and out of the room, and everyone seems to speak in “another” language. For example, people don’t have a bruise; they have a “hematoma”--which is exactly the same thing as a bruise. For family members, getting questions clearly answered is not so easy.

First, it is important for family members to educate themselves. Read about brain injuries. The internet is a resource but be careful about the source of the information. Don’t believe everything you read! Be sure the information is from a credible source, such as the Brain injury Association of Connecticut. The goal of this education manual is to educate you to improve your knowledge of brain injury. It is a home reference guide that can be referred to when questions arise. Gaylord also has an extensive library with many resources available.

Gaylord Specialty Healthcare runs a Support Group for **Families & Caregivers of Patients with Acquired Brain Injury**. This program offers a four week series with specific information each week. Families and caregivers are strongly encouraged to attend the entire series. The goals of the program are:

1. To provide families and caregivers with fundamental information about common symptoms and challenges after brain injury.
2. To help family members better understand how the injury has affected each member of the family and the family as a whole.
3. To teach families and caregivers a variety of strategies which will enable them to problem solve more effectively and more efficiently to achieve personal goals.
4. To teach coping strategies that facilitate the process of emotional recovery, helping each family member to feel better about themselves.
5. To instill hope by identifying progress and personal strengths.
6. To teach family members effective communication skills in order to develop a strong, mutually beneficial long-term support system.

**Important Family Considerations while in the Hospital**

**Stimulation**

Family members and friends often want to know how to help with the confusion and agitation phase. One strategy is to reduce stimulation. In the early recovery period, someone who gets a lot of stimulation during the day may often become agitated or confused in the late afternoons or evenings. Some stimulation is an unavoidable part of the normal day. For example, there is speech therapy, occupational therapy, and physical therapy during the day.

The person with a brain injury can become very tired by the challenges of these activities. By the evening (or even earlier), it might only take minimal stimulation to get someone agitated. Try to decrease stimulation in the room. Close the blinds and keep the TV off while visiting. Family members should try to limit decorations or cards in the room because it can be visually distracting and overwhelming. The number of visitor should be limited to 1-2 people at time and should be short in duration.
Communication

It’s not what is said, but the tone of the voice that’s important. All people tend to listen better when spoken to in a calm manner. After a brain injury, speaking slowly and calmly is even more important. Use short sentences or even single words, such as, “Hungry?” “Are you in pain?” “Show me where you are in pain.” The individual with a brain injury may have problems understanding long sentences. Although the patient may speak in long sentences, the ability to understand may be limited (talk to the patient’s speech therapist about this). Also, be aware that it may take a longer time for the patient to respond to questions than it did prior to the injury.

Another common question from family members is whether or not they should correct the patient when they say something silly or incorrect in the early confusion and agitation phase. For example, the person may be saying, “I want out of this hospital so I can go skiing.” Many family members may debate with that person saying, “No, it’s not winter,” or “No, you need medical care.” Patients, who are confused or agitated, won’t really understand logic or reasoning.

When someone is very confused, it’s better to change the topic of conversation. Distract them by saying “How about a walk? You want something to drink?” Talk about their favorite hobbies or things they enjoyed doing. In general, people with brain injuries have good long-term memory (things that happened years ago) but their memory of recent history may be impaired. Using old information may be comforting to some people.

Healing Touch

When visiting a patient with a brain injury, physically touching them may not always be a good thing. Many times in American culture, touch is used as a reassuring gesture. When people are crying or upset, it’s natural to put a hand on theirs, or give a big hug to reassure them. In the early phase of a brain injury however, that may not be beneficial. It may make the person very agitated because their space is invaded. Some individuals with a brain injury can be hypersensitive, where a simple touch is often perceived as pain.

Outside Communication

One thing that often overwhelms family members is the constant need to update other family members and friends. Some family members come to the hospital and spend the day or evening with the patient only to go home and have 50 people calling them to ask, “Well, what happened in therapy today?” One or two family members can give updates to a few other family members, who, in turn, can take on the task of returning the phone calls and distributing the updates. Perhaps developing a phone tree would help pass on the updated information. There are websites, such as CaringBridge.org, that can help communicate the person’s status to large groups of people.

After Leaving the Hospital

After all the stress of the hospital stay and all the unknowns, going home is a very big event for family members. As exciting as it is, it’s just the beginning of the recovery process. The medical injuries, such as the broken bones are likely healed. However, healing from a brain injury can take years. When someone goes home, many family members think, it will just be just a couple more months. In truth, it’s usually a lot longer.

In the months following discharge from the hospital, it’s important to remember that the individual with a brain injury may fatigue easily.

When a person with a brain injury gets home from the hospital, they may have only 3 or 4 good hours in the day before they’re wiped out. They may easily fall asleep, or they may not be able to concentrate. Some individuals may be better in the mornings than in the evenings. It is important for family members to remember this and adjust appointments, visits, and plans, accordingly.

In the early weeks, it is suggested to try to limit “welcome home parties” and visitors. Instead, try a welcome home party that lasts for about an hour, and then ask everyone to leave. The individual with a brain injury may want to see friends right away, however, they may have limited awareness of their tolerance for activities and socialization. Family members may need to step in and limit visits to 1 or 2 hours, depending on how much the person can tolerate. However, being too strict about time limits can lead to depression and feeling isolated from friends. It is always a very careful balancing act.
Many times, families find it difficult to treat the person normally. Family members may unknowingly talk down to the person or treat them with pity, or as if they are no longer an adult. The individual with a brain injury wants to be treated like everyone else— with RESPECT.

It’s important to note that some friends will be uncomfortable talking about the injury. They may harbor thoughts of “this could have been me,” and talking about it scares them. Other visitors may be afraid to speak with the individual for fear of upsetting him or her. Others may engage in an in depth discussion about the brain injury.

A brief acknowledgment of the person’s injury is best. If the injured individual wants to discuss the injury further, let him or her take the lead. Many times this is not the case, as they want to get on with life and discuss topics not related to the injury. They might like to focus on the things they love to do, or catch up on what’s happened when they were in the hospital. It’s important to try to normalize conversations.

Family members often have difficulty dealing with someone who looks the same but is different. People who have had a brain injury may talk the same and walk the same, but will be emotionally or behaviorally different. For example, they may be more irritable, or more cranky, and perhaps more impulsive. For family members, it’s very hard to deal with this. It’s almost if someone has come in and stolen their personality. This can also lead to a loss of friends. Although this is not true of everybody, it is a common problem.

The family can encourage the person to make new relationships. Meeting people who did not know the person before the injury will have no idea how they acted prior, and can be more accepting.

Often new friends might not be as cautious as a family member might be regarding the individual with a brain injury’s mobility and abilities. There is always some risk that the person may fall or be injured. Although family members want to prevent any further harm to the injured person, nothing in life is risk-free and family members may have to encourage this independence. The individual with a brain injury needs to get out and be with friends, away from the sometimes protective cocoon of families. Again, it’s a difficult balancing act, but new activities must be encouraged.

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**SECTION 4**

### Predictors of Recovery

#### Recovery

The most common question asked is, “When will I get better?” And, the most common or best answer is “I don’t know.” There is no objective measure that can ensure how long recovery will take. One measure of recovery is to look at complex thinking and subtle changes in behavior. Psychological tests that measure changes in thinking or memory. Research does show the greatest improvement in test scores for the first six months post injury, however progress can continue for months or even years after this. After two years, the changes in scores tend to be very slight. Does this mean that people stop getting better after two years? No. There are many patients in long-term support groups who continue to report progress after this time frame.

“Am I ever going to be “100 percent” following my brain injury?”

The universal answer in most instances is no. Some people, who have had significant brain injuries, are able to return to work, regain a normal family life, and seem to be doing great. They participate in social activities, get promotions at work, and earn a living; yet they still say, “I just feel different.”

#### Predictors of Recovery

Predicting the outcome of a head injury is complicated. Medical tests are not always the best predictors of long-range recovery. Imaging studies, such as a CT scan or MRI, can identify bleeding in the brain and the site of injury; but, these studies cannot predict the degree of recovery. Obvious signs of physical injuries are also unreliable predictors of recovery. Some people present to the hospital with only “minor” physical injuries, those that can be seen, and are discharged within hours of the accident. Others are in a coma with multiple physical injuries. No one can predict the outcome, in either case.

Studies of the brain injured population have identified certain inherited and acquired forecasters of recovery including: intelligence, education, and prior substance abuse, among others.
Pre-Injury Intelligence

Pre-injury intelligence (IQ) is a factor in recovery. In general, people having a higher IQ will have a better outcome than similar people with a lower IQ. The emotional impact may be more severe for those having a higher IQ and they may have more difficulty adjusting to their changed circumstances. Perhaps before the injury, they could think quickly, make speedy decisions, and have ready solutions to problems. After the injury, these tasks may be harder to accomplish and the injured person may feel “different”, not their “usual self.”

Education and Academic Skills

Another positive factor in recovery is the amount of education person received prior to the injury (high school diploma, college degree, etc.). Strong academic skills can be, but are not always, an asset in recovery.

History of Substance Abuse

Studies have found that the use of drugs and alcohol is a negative predictor of recovery. Abusing alcohol and or drugs or many years results in the loss of a large number of brain cells; brain cells do not grow back. Alcohol tends to attack areas of the brain responsible for short-term memory. It is important to stop using alcohol and drugs following a brain injury. Those who continue to use drugs following a brain injury have a worse outcome.

1. People who use alcohol or other drugs after they have a brain injury don’t recover as much.
2. Brain injuries cause problems in balance, walking, or talking that get worse when a person uses alcohol or other drugs.
3. People who have had a brain injury often say or do things without thinking first, a problem that is made worse by using alcohol and other drugs.
4. Brain injuries cause problems with thinking, like concentration or memory, and using alcohol or other drugs makes these problems worse.
5. After brain injury, alcohol and other drugs have a more powerful effect.

6. People who have had a brain injury are more likely to have times that they feel low or depressed and drinking alcohol and getting high on other drugs makes this worse.
7. After a brain injury, drinking alcohol or using other drugs can cause a seizure.
8. People who drink alcohol or use other drugs after a brain injury are more likely to have another brain injury.

Helpful Resources

There are positive steps to take during the aftermath of an injury, including the following:

Support Groups
Check out the Brain Injury Alliance of Connecticut (BIAC) website for the most up to date schedule of local support groups at www.biact.org

Chemical Use Education (CUE) Group at Gaylord
CUE group is a 30 minute weekly group facilitated through the Social Worker under the Department of Psychology. This group serves several purposes, including: (1) providing general education about substance use, and resources regarding the effects of substance use and behavior and continuing rehabilitation efforts, (2) helping patients make informed, healthy lifestyle decisions moving forward, and (3) screening for patients who could benefit from treatment for chemical dependency.

Work on Memory Techniques and Organizational Strategies
Gaylord’s brain injury program will strive to help the injured person improve skill recovery and teach coping strategies for what cannot be improved. The goal is for the individual to learn the tools to continue with his/her own recovery.

Prevention and Nutrition
Simple preventative measures can help limit any further injury or slow recovery. It is best to avoid roller coasters and wear a helmet when biking, skateboarding, or riding a motorcycle. Do not participate in activities that have the potential of further injury unless you have clearance from a medical professional.
This includes driving. Other activities to avoid are using ladders, power tools, or firearms. Eating a well-balanced diet, maintaining an ideal weight and getting physical activity will all improve recovery.

The brain is the most complex machine in the world. The good news is that people do recover lost abilities and can live a productive life. Patience and persistence coupled with working hard and a positive attitude will produce results. Every marathon starts with a single step.

There are a number of common emotional stages that people with a brain injury go through. It is important, however, to remember that each patient’s recovery is unique, and it may vary from the stages listed below. Also, not everyone experiences the stages in the same order, and some may experience multiple emotions at the same time.

**Confusion and Agitation**
Confusion and agitation after a brain injury can last minutes or months. It can start as soon as the injury occurs. Once in the hospital setting, the person may not know where they are or what has happened to them. They may become disoriented, agitated, and restless. People with a brain injury are very anxious at their own disorientation, and families become upset at the change in person’s behavior.

The person with a brain injury may be physically aggressive or swear and curse at family members. This can be very frightening for family members and it can feel like it is going to last forever. For the majority of patients, however, this phase does go away. It may take a while, but people usually come through this stage due to the therapeutic environment, medical intervention, and supportive counseling. It is also important to note that most individuals have no memory of this phase or the events that took place during it.

**Denial**
The next emotional phase is usually denial. Denial, or lack of insight and awareness of their deficits can be very difficult for both family members and medical staff. The individual with a brain injury may say, “Yes, I can drive,” but family members know that it would be dangerous. During this phase, it is important to give consistent and direct feedback reminding them that everything is not “okay”.

**Anger and Depression**
The next phase of recovery is anger and depression. This occurs when the individual continues to have limited awareness of the brain injury. They realize they are different and cannot do things they did prior to the brain injury. This can lead to anger and depression.
Some people think of depression as anger turned inward. People will tell themselves, “I’m a failure. I can’t do this. I’m no good.” On the other hand, people who are struggling to deal with the vast changes produced by a brain injury may get angry at people around them. They may feel as if their family is not being supportive or understanding their injury.

Some of this anger may also be due to the area of the brain that was affected. The anger may come on extremely quickly, often going from “zero to 60” in a matter of seconds. The areas of the brain that control those emotions have been injured and irritability and a reduced frustration tolerance are common.

Not all anger or depression is due to physical changes in the brain, however. Instead, it may be an emotional way of coping with things. Most individuals who have a serious illness or injury will have some anger and depression. If the injury was due to a car accident, the individual may be angry at the person who ran into them or they may be angry at themselves for getting into an accident.

Sometimes anger is justified, as when the accident was due to a drunk driver. When people have difficulty dealing with overwhelming situations, they often blame themselves. They may dwell on thoughts such as “If I had only left my house five minutes later or five minutes earlier, I wouldn’t be in this mess.”

**Testing Phase**
The next phase almost always follows after a period of recovery and improvement in thinking abilities. When individuals realize they are improving, they go through the **testing phase**. Basically, they test themselves to see their limits. This often involves some degree of denial on their part. The person thinks “I’m getting better. Let’s see if I can do things as I did before.” Although they know that they tire easily; during this testing phase, they might say, “Well, my friends are visiting this weekend. I’m going to stay up really late.”

**Uneasy Acceptance**
The last phase is **uneasy acceptance**. Individuals with a brain injury learn where they stand and what their limits are. They realize, after many failed attempts, that they can only handle a limited number of hours of work or play. They have learned to keep a consistent schedule and will stick to that schedule.
Augmentative and Alternative Communication

Augmentative and alternative communication (AAC) incorporates the communication methods that are used to supplement or replace speech or writing for those with difficulty producing or understanding language. AAC is used by those with a wide range of speech and language impairments. AAC can be a permanent addition to a person’s communication or a temporary aid.

The purpose of AAC is to facilitate meaningful participation in daily life activities. Special augmentative aids, such as picture and symbol communication boards and electronic devices, are available to help people express themselves. This may increase social interaction, performance, and feelings of self-worth. AAC should be used when communication needs are not being met, and to allow the individual to express his or her own feelings, thoughts, wants, and needs.

A team approach is utilized when providing AAC services. A SLP will identify the need for AAC and will perform an assessment to determine the most appropriate AAC techniques and equipment. The SLP then develops material, programs a device, and trains the patient, family, and other team members regarding its use. An OT also plays a role in determining the most effective ways to access communication aids. A PT will determine the most effective positioning for the patient.

Assistive Technology

Assistive technology (AT) is any item, piece of equipment, or product system that is used to increase, maintain, or improve functional capabilities. AT can be off the shelf, modified, or customized. AT enables an individual with a brain injury to fully participate in meaningful activities and fulfill life roles. Trained therapists work collaboratively with individuals to determine the most effective and efficient piece of AT to meet individual needs. Therapists may recommend devices to help people be more independent with feeding, bathing, dressing, communicating, cooking, and/or accessing their home environment.

AT also includes devices that increase your mobility, computer access, and communication. AT may be considered ‘low tech’ or ‘high tech’. Low tech equipment may include a long handled reacher or elastic shoelaces. High tech equipment may include an environmental control unit that can control lights and simple appliances in your home.

AT also includes making adaptations to existing equipment to increase the level of function. Therapists work with both the individual with a brain injury and the family to determine specific goals and objectives. While the individual with a brain injury is an inpatient, the therapy and medical team will begin to introduce a variety of assistive technology that meets the individual’s needs. Gaylord staff will be able to provide the individual with a number of resources and will introduce and trial AT products if appropriate.

What Does Gaylord Have?

Standing Frame

A standing frame is a device that allows the individual with a brain injury to be supported in a standing position if they have weakness in the torso and legs. Regular use of a standing frame can minimize many complications that can be experienced due to sitting in a wheelchair for too long. The potential benefits of using a standing frame include:

• Maintaining full movement in the hips, knees, and ankles
• Improving postural alignment
• Reducing muscle spasms
• Relieving pressure on the skin
• Reducing fatigue
• Increasing confidence and improving mood

Lite Gait™

The Lite Gait™ is a body-weight supported harness system that is used in therapy to assist an individual with standing and walking if he/she is having difficulty with these tasks.
**Walk Aide™**

The Walk Aide™ is a device to help decrease “foot drop”. After a brain injury, it is not uncommon to have weakness in the leg, foot, and ankle, which can often result in foot drop, or the inability to pick the foot up while walking. The Walk Aide™ is a device that assists in providing electrical stimulation to help strengthen the weak muscles. The PT can discuss and make recommendations as to whether or not the Walk Aide™ device will help with recovery.

**Ekso™**

Ekso™ is a wearable battery powered, bionic device or exoskeleton that enables people with lower extremity paralysis or weakness to stand and walk. With the individual providing the balance and proper body positioning, Ekso allows them to walk with reciprocal gait. The physical therapist uses the control pad to program the desired walking parameters, such as step length and speed, as well as control when the Ekso stands, sits, and takes a step. The variable assist feature allows the device to provide varying levels of power to each leg, allowing the individual to use their own muscles to the best of their ability and progress in their recovery.

**MYOMO™**

The MYOMO™ is a robotic device that the therapist may utilize during treatment as indicated. The MYOMO™ is an FDA-approved device for use with individuals who have had a brain injury and have arm weakness. The MYOMO™ is designed to improve arm function and increase independence in persons following a brain injury. The device allows the individual to initiate and control movement in the weakened arm. The use of the device is non-invasive and does not involve electrical stimulation of the muscle.

**Functional Electrical Stimulation™**

Functional electrical stimulation is the clinical use of an electrical current to cause a contraction in a muscle. When electrical stimulation causes the muscles to contract in a purposeful way, this is called functional electrical stimulation or FES. Bioness™ is a device that Gaylord uses for muscle re-education. It is specifically designed to be utilized with individuals who have weakness in one or both of their arms following a brain injury.

Gaylord also has Bioness H200 Wireless Therapy™ available for use with individuals with impaired arm and hand function. The Bioness H200 Wireless is the only device FDA-approved to improve hand function. Clinical benefits of the device include improving hand active range of motion and hand function, improving voluntary movement, re-educating muscles, maintaining and increasing range of motion, increasing local blood circulation, and reducing muscle spasm. The OT may suggest use of this device to improve hand function if indicated.

Another Bioness device in use is the L300 Plus. It is a system that uses electrical stimulation to control foot drop and improve knee stability. The system’s gait sensor adapts to changes in walking speed and terrain. The L300 is programmed by the physical therapist to stimulate the appropriate nerves and muscles in the leg to lift the foot, stabilize the knee, and help with a more natural walking pattern.

**Vestibular Technology (VORTEQ, DVA-T, VHIT and binocular video goggles)**

Gaylord has specific technology to help diagnose and treat issues with the vestibular system. After a brain injury, the vestibular system (“inner ear”) can be affected causing dizziness and visual issues.
We use special goggles and video recording devices to measure speed of motion, responsiveness, and reaction of the eye to various movements and positions. Graphs representing the eye movements can be plotted to give a visual depiction of functional problems and help guide treatment.

**Positioning and Related Equipment**

Proper positioning can be crucial for a variety of reasons. How a patient is positioned in bed or in a wheelchair can assist in maintaining proper joint alignment, range of motion, and comfort. Common areas of concern include: head and neck, trunk alignment, arm, leg, and any bony prominences such as elbows, heels, and buttck/pelvic bones. Common items used for positioning may include: pillows, wedges, multi-podus boots, and towels. These items can be utilized in bed to elevate such areas and protect the skin from breaking down. The entire rehab team frequently monitors skin for any vulnerable areas of redness. The therapy team will work together to choose an appropriate cushion to ensure comfort and adequate pressure relief/distribution while a patient is seated in a wheelchair.

In addition to skin protection, positioning is important to protect the affected limbs after a brain injury. Most commonly after a brain injury, an individual’s arm is initially very weak and needs to be supported while in a seated or standing position. The humerus bone/upper arm bone may start to separate from the shoulder joint since the muscles that typically support the shoulder joint are weak or inactive. This can lead to pain and subluxation of the joint. The occupational therapist will choose an arm tray or trough to help keep the arm supported (and elevated if needed) and the shoulder joint in alignment while the individual is seated in their wheelchair. It is also important to maintain a safe position of the shoulder during transfers and walking. The OT may also suggest a sling for use during these activities.

The OT may also recommend use of a hand splint for the affected extremity to maintain soft tissue length and to protect the hand joints while at rest. This splint is often called a resting hand splint. The OT will work with the individual and his/her family to develop a wearing schedule and provide education for how to put the splint on.

The staff will work with the individual and their family to provide appropriate positioning to maintain proper joint alignment and maximize comfort and hygiene. If necessary, contact information of the vendor who made the splint will be provided to assist the person as needed with any changes to help improve comfort and fit of the splint.

After a brain injury, individuals often have difficulty moving the affected side of their body. Over time, this lack of movement may cause an increase in fluid buildup in the hand or foot. A foam wedge and/or Isotoner™ glove may be issued to help more evenly disperse the fluid.

The tight white stockings, known as TEDS or compression stockings, are used similarly for the legs. These stockings are also used to assist with circulation in the legs since the individual may not be as mobile at this time.

**Taping**

Kinesiotape is a therapy tool used to assist people in offering support to weak muscles in either the arm or leg that can become painful after a brain injury. It is another method that can be used to protect the shoulder joint and assist with the prevention of subluxation. The physical therapist and occupational therapist will answer any questions about the use of kinesiotape in recovery after a brain injury.

**Bracing**

After a brain injury, it is common to see weakness affecting the leg. This weakness can have a negative effect on one’s safety with transfers (moving from one place to another), walking, and stair negotiation. The physical therapist will make recommendations as needed for bracing for the weak leg. These may include an aircast (to help stabilize the ankle), an ankle foot orthosis (AFO), or multipodus boot to provide a stretch at the ankle to prevent loss of range of motion.

The PT will also help the individual with a brain injury understand why the brace/orthotic is important and how to put it on and take it off. They will also determine a wearing schedule and educate on the importance of checking the skin while wearing a brace.
The contact information of the vendor who made the brace will be provided to assist as needed with any changes to help improve the comfort and fit of the brace, or orthotic. Gaylord has a Prosthetic and Orthotic clinic on Mondays to help determine the best orthotic for the individual on the therapist’s recommendations.

Early Recovery Program
On occasion, some patients are not fully ready and able to start in an intense and aggressive inpatient rehabilitation program. They need to begin at a significantly slower pace. The Early Recovery Program has been designed to start the inpatient rehabilitation process in a specifically patient centered fashion. These patients with brain injuries have had such extensive neurologic injury that their level arousal or endurance is very limited. They require prolonged and complex medical/nursing care.

The Early Recovery Program focuses initially on the ‘building blocks’ to function rather than a specific functional goal. Treatment also focuses on the profound deconditioning and ongoing management of multiple medical/nursing matters. Therefore, patients enrolled in the early recovery program have fewer initial functional goals and more time to complete the ‘building block’ goals established.

In the continuum of rehabilitation services, Early Recovery provides more therapy than what is provided by consistent trained therapists at an acute care hospital but notably less than that of an intense acute rehabilitation program. Ongoing medical management and intensity of nursing care also takes priority. Because of the slower pace in recovery, patients may remain in the early recovery program for a longer period of time, but not indefinitely. The goal is to transition a patient from the slower ‘building block’ program to one that focuses on functional gains achieved in a reasonably timely fashion. For those who can make this transition, it should happen within 8 weeks from the time of admission.

Occasionally even when good progress is made in the early recovery program, there may not be the functional gains or improvements with endurance made to support the transition to acute rehabilitation. This can suggest a slower path to recovery that becomes best provided in a subacute rehabilitation setting rather than acute.

Community Re-Entry
Community Re-Entry is a group therapy session offered at Gaylord Hospital.
The purpose of community re-entry is to provide an opportunity for exposure to potential community barriers, increase knowledge of leisure resources in the community, increase skill building through off-site therapy intervention, provide opportunity for social interaction, and increase physical and/or cognitive functioning. There are specific entrance criteria for the group including but not limited to: having a discharge plan to a less structured environment (ex. Home, Traurig House) and being medically stable and cleared by the physician to leave the hospital for 1 ½ hours for a community trip. Referrals for community re-entry are made by treating therapists during therapy meetings when the group is appropriate to run.

Transitional Living

The **Louis D. Traurig House** is the only transitional living center for people with acquired brain injuries in Connecticut. Located on the Gaylord Hospital campus in Wallingford; Traurig House is an 8-bed, co-ed facility. The setting is that of a home with bedrooms, sitting areas, a computer station with internet access, a kitchen, and a dining room. Typically, residents come to Traurig House after they have completed their inpatient rehabilitation but are not quite ready to go home because of difficulty with language, physical, or cognitive functioning. Traurig House provides the necessary transition to ease the patient from hospital to home.

Many private commercial insurances cover Traurig, however, it is best to consult individual coverage plans. Medicare does not have a Traurig benefit. The average length of stay for residents is individualized, and is determined by the interdisciplinary team (IDT) that consists of the therapists and the residential staff. The resident and family participate in the decision making regarding length of stay and follow-up services. Individuals in the Transitional Living Program receive services in our Cognitive or Aphasia Day Treatment Program at Gaylord Hospital’s Outpatient Department. The comprehensive Day Treatment Program consists of two distinct programs. One is designed for those people who are experiencing cognitive challenges and the other for those who have developed aphasia or a language impairment.

These Day Treatment programs offer an intensive, structured group program, in addition to individual therapies aimed at returning each person to their maximal function in a supportive and caring environment.

The residents have weekly goals in the house to progress their functional skills toward independent living and maximize their potential under the supervision and assistance of staff. The Traurig House allows an individual and his/her family to “practice” what it will be like when the individual returns home. Tours of Traurig are available by calling: (203) 741-3488 or (203) 284-2773.

**Gaylord Outpatient Services**

The Outpatient Department at Gaylord offers physiatry, physical therapy, occupational therapy, speech therapy, psychology and aquatic therapy. The clinicians at our Wallingford campus specialize in the treatment of neurological conditions that include, but are not limited to, Acquired Brain Injury, Spinal Cord Injury, Multiple Sclerosis, Guillian Barre Syndrome, and Parkinson’s Disease.

Each individual is evaluated to determine their clinical need, and a customized treatment program is established to meet the needs of each client. We also offer clinical care in specialty areas such as a Customized Wheelchair Clinic, Prosthetic and Orthotic Clinic (for those who require custom fit braces), Audiology Services (the Hearing Center), Pulmonary Rehabilitation, and Nutritional Consults.

The Outpatient Department also provides therapy for all residents of the Louis D. Traurig House Transitional Living Center. The comprehensive, coordinated Day Treatment Program (as noted in the Transitional Living section above) accommodates the two distinct groups who are experiencing cognitive challenges or who have developed aphasia or a language impairment. Individuals may be referred for one or a varied combination of these services. Our scheduling department strives to offer a schedule that is as efficient and as convenient as possible. One may contact the Outpatient Service by calling: (203) 284-2888.
Returning to Work and School

Consideration for an individual with a brain injury to return to school or work occurs towards the end of treatment. Certain steps must be followed to ensure a successful transition back to school or work. This includes testing, adequate communication between the medical team and the school or work setting, and arrangement for special accommodations. Becoming connected with resources in the community or national organizations can also be helpful with this process.

Consideration for return to work/school is based upon the recovery of functions in numerous domains. These domains include cognition, behaviors, physical skills, and emotions. Cognition allows us to acquire new information, process that information, and retain it for later use. Cognition also impacts all other aspects of functioning. For example, behaviors are influenced by our ability to recognize and filter social expectations and interpersonal interactions. One must be able to understand and remember information to respond appropriately and generalize behaviors to other settings, especially in the return to pre-injury functions and environments (e.g., home, academia, employment). As well, it is important to recognize our own abilities and limitations (self-awareness) in the context of recovery to utilize the information we receive from our environment, treatment providers, family, and friends.

Behaviorally, one must be able to interact with others and their environment to successfully engage in activities and relationships with others. Emotionally, individuals may experience changes in mood and affect the expression of mood. This in turn, can affect how one reacts to incoming stimulation and may lower one’s resistance to frustration and heightened sensitivity to the environment and other individuals with whom they interact. Depression and anxiety are common emotions during recovery. Individuals and their families may experience a grieving process during recovery, all of which may impact returning to pre-injury activities and settings.

Driving

Driving should not occur for several weeks to months following a brain injury. Weakness, impaired motor planning, visual/perceptual compromise, neglect, impaired cognition, decreased attention, impulsivity, decreased problem solving and executive function, may directly impact performance with the complex task of driving. The interdisciplinary team will help determine when someone is ready for a formal driving screen prior to resuming this activity.

Sexuality

Many individuals with a brain injury report altered sexual function. Research suggests that there may be some physical components to this problem, but that psychosocial issues are more common. Sexual activity is a normal part of life for many people and a brain injury rarely affects sexual function itself. Due to weakness or paralysis, sex may be easier in different positions than you used before. A brain injury may affect your emotions or confidence in a way that may affect your relationship. Willingness to discuss these issues with healthcare providers and partners is encouraged and no reason to be embarrassed.

Leisure

Recreation can reduce the chance of secondary diagnoses, such as depression. Participating in recreation regularly can improve self-esteem, promote relaxation and stress reduction, increase physical fitness and function, expand social interaction, enrich quality of life, increase knowledge and skills, and decrease the chances of being readmitted to a hospital. Some examples of recreational activities include:

A neuropsychological assessment is generally conducted upon referral from one’s treatment provider to examine the strengths and weaknesses of cognitive, behavioral, and emotional abilities. The test results help to guide treatment and determine what accommodations would be necessary to foster a smooth and successful transition back to one’s environment. This evaluation may occur briefly during the inpatient stay, but most often is scheduled post-discharge when patients are seeking to resume pre-injury activities. The individual with a brain injury and/or a family member typically consult with the physician, physician’s assistant, or therapist to initiate the referral process. Results of the testing and recommendations that stem from the testing are reviewed with the individual with a brain injury (and family if desired) to aid implementation.
The Sports Association provides adaptive sports and recreational opportunities for individuals with physical disabilities such as spinal cord injuries, brain injuries, amputations, pulmonary disorders, and visual impairments. The Sports Association is the Paralympic Sport Club of Southern New England, and aims to enhance the lives of individuals with various ability levels. It also aims to assist athletes with disabilities in attaining the highest level of independence possible in a variety of sports and recreation pursuits.

There are over a dozen sports offered that feature various ways of participating, learning, and exploring the sports and activities. Examples of sports offered are:

- Archery
- Adaptive Cycling
- Climbing
- Fishing
- Golf
- Kayaking
- Wheelchair Rugby
- Downhill Skiing
- Sled Hockey
- Tennis
- Paratriathlon
- Water Skiing

Some ways to participate are:

**Clinics:** Hands-on experience and expert instruction in Kayaking, Golf, Tennis, Archery, and Cycling

**Clubs:** Clubs offer regular outings in downhill skiing, water skiing, and golf.

**Teams:** The Sports Association is proud to sponsor the Connecticut Jammers Wheelchair Rugby Team, the Gaylord Sports Association Wolfpack Sled Hockey Team, and the Connecticut Hornets Wheelchair Tennis Team that compete throughout the region.

**Tournaments:** Tournaments in Wheelchair Rugby, Wheelchair Tennis, and Golf offer athletes healthy competition and team camaraderie.

For more information, please call 203-284-2772 or visit our website at www.gaylord.org

**Home Safety and Modifications**

If a loved one is being discharged to home, there may be many home modifications, adaptations, and recommendations that can be made to the home to increase safe and independent functioning. A therapist can make many suggestions to the family after asking several questions and/or seeing pictures of the house set up. An OT or PT can answer any specific questions one may have about the home.

**General Considerations**

- Type of home: one-family, two-family, apartment, condo, etc.
- Number of entrances
• Steps to enter/steps within the home, need for ramp
• Presence of railings
• Door sills
• Width of entrances
• Identification of obstructions of pathways
• Carpets
• Electrical cords
• Accessibility of light switches, telephones
• Presence of working smoke detectors
• Presence of space heaters or wood burning equipment
• Presence of an emergency call system/exit plan
• Presence of pets

**Common Recommendations**
- Ensure adequate lighting
- Use contrasting colors
- Simplify environment, reduce clutter
- Arrange furniture for easy maneuvering
- Firmly attach carpet
- Securely fasten handrails on both sides of stairs
- Provide light switches at top and bottom
- Install non-skid surface
- Fix cracked pavement or steps
- Install outside hand rail
- Encourage use of rubber-soled or low heeled shoes

**Considerations Specific to Room:**

**Bedroom**
- Size and height of bed/top of mattress
- Position of bed (free standing vs. against a wall)
- Side of bed person will enter/exit bed
- Accessibility of clothes and dresser drawers
- Sufficient space for bedside commode if needed

**Common Recommendations**
- Install night lights, or light switch within reach of bed
- Place telephone within reach of bed
- Raise or lower bed height as needed
- Arrange furniture for easy maneuvering

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**Bathroom**
- Number of bathrooms in the home: location and accessibility
- Width of bathroom doorway
- Height of toilet and tub
- Type of bathing person performs (shower, bath, sponge bath, etc.)
- Type of shower (shower stall, tub/shower, glass door/curtain closure)
- Presence of grab bars
- Location of soap dish
- Presence of hand held shower
- Presence of anti-scald valves and/or faucets

**Common Recommendations**
- Install grab bars where needed
- Provide non-skid mats and night lights
- Use elevated toilet seat

**Kitchen**
- Locations of frequently used meal prep devices such as microwave, oven, stove, etc.
- Presence of countertop area between stove, sink, and refrigerator
- Accessibility of food, pots, pans, dishes, and preparation materials
- Presence of charged fire extinguisher
- Presence of anti-scald valves and/or faucets

**Common Recommendations**
- Store items on reachable shelves (between person’s eye and hip level)

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**Fall Prevention**

**Four Things to Prevent Falls**

1. Begin a regular exercise program.
   - Exercise is one of the most important ways to lower the chances of falling. It makes one stronger and helps to make one feel better.
   - Exercises that improve balance and coordination like Tai Chi are the most helpful.
   - Lack of exercise leads to weakness and increases the chances of falling.
   - Ask the doctor or therapist about specific exercises.
2. Have a health care provider review medicines.
   • Have one's doctor or pharmacist review all the medicines one takes, including over-the-counter medicines. As one gets older, the way medicines work in the body can change. Some medicines, or combinations of medicines, can make one sleepy or dizzy and can cause falls.

3. Have vision checked.
   • Have the eyes checked by an eye doctor at least once a year. One may be wearing the wrong glasses or have a condition like glaucoma or cataracts that limits vision. Poor vision can increase chances of falling.

4. Make the home safer.
   About half of all falls happen at home. To make the home safer:
   • Remove items that one can trip over (like papers, books, clothes, and shoes) from stairs and places where one walks.
   • Remove small throw rugs or use double-sided tape to keep the rugs from slipping.
   • Keep items that are often used in cabinets one can reach easily without using a step stool.
   • Have grab bars put in next to the toilet and in the tub or shower.
   • Use non-slip mats in the bathtub and on shower floors.
   • Improve the lighting in the home. As one gets older, one needs brighter lights to see well. Hang light-weight curtains or shades to reduce glare.
   • Have handrails and lights put in on all staircases.
   • Wear shoes both inside and outside the house. Avoid going barefoot or wearing slippers.
   • Paint a contrasting color on the top edge of all steps so one can see the stairs better. For example, using a light color paint on dark wood stairs will increase the visibility of steps and decrease chances of falling.

Emergency Preparedness

It is key to have a plan before an emergency takes place. There are many agencies that can help you in making your plans. The Ready.gov website has videos, plans, supply kit checklists, and helpful tips. FEMA and the American Red Cross has many other ideas to help you. For more information, see the resource section below.

When making your plan, think about the needs of the people in your home. Create a contact list to be shared with other family members, caregivers, and neighbors. You will also need contact information for important offices and people such as doctors, hospital, utility company, pharmacy, etc. Letting first responders know there is a person with disabilities in the house may be helpful in an emergency. Make an emergency kit with:
   • all contact information
   • an up to date medication list
   • any backup medical devices or assistive technology needs

Practice your plan with your family and friends. Just like fire drills, emergency drills are the best way to see if all your needs will be meet before it counts. If possible, store any emergency supplies:
   • over-the-counter medications
   • insulin
   • catheters
   • ostomy supplies or any other medical supplies
   • bottled water
   • non-perishable food
   • modified textured foods
   • thickened liquids
   • flashlights, radio, batteries

If an emergency evacuation takes place, you will be able to provide first responders your information, needs, and where you hope to stay. If you or someone in your home has a wheelchair, it’s important to know the size and weight of it in case it needs to be transported. You might want a collapsible transport wheelchair for backup. If oxygen is needed, back up tanks and portable concentrators also need to be planned for.

Protecting yourself and your family in an emergency takes planning. By having contact lists, your emergency kit, and a plan can make it much less scary. Know how to get the help you need. Be sure to practice and be prepared.
Self-Advocacy

It is important the brain injury survivor and the family advocate for themselves. The world of healthcare can be overwhelming. There are many resources in the community that can help navigate this new world. Many are listed in the next section.

One of the best places to start is BIAC, the Brain Injury Alliance of Connecticut, www.biact.org. One also needs to advocate in each medical appointment. In order to get the most out of your time with your provided, come prepared with a list of your medications and your questions. Bring a family member of friend to be a second set of ears and to take notes. Ask about side effects and other options for treatment.

One of the hallmarks of a good patient-healthcare provider relationship is open and honest communication about problems. Difficult discussions about feelings of abuse or neglect are important to have with medical professionals. Abuse can come in many forms; physical, emotion, verbal, psychological, financial or sexual. Neglect, intentional or not is also considered a form of abuse. In the event of suspected incidents of abuse or neglect, we encourage patients, families, and staff to report the situation to any healthcare provider. We are mandatory reporters and serve to protect those in our care. Incidents of actual or suspected neglect or abuse, whether committed by family, healthcare workers, or others, are thoroughly investigated by the state government. If you have any questions, please speak with your healthcare provider.

Education is an important part of advocacy. The potential role of CAM (Complementary and Alternative Medicine and Therapy) can be reviewed at various websites and resources including:

- National Brain Injury Association website www.braininjury.org; and search for current articles on the topic in issues of their magazine Brain InjurySmart
- Cochrane Collaboration website www.cochrane.org
- The National Institutes of Health National Center for Complementary and Alternative Medicine (nccam.nih.gov/health/whatiscam/) Research studies and clinical trials are available as well. Many websites can be accessed regarding clinical studies, including the National Institute for Health http://www.ninds.nih.gov/disorders/tbi/detail_tbi.htm.

Resources:


6. Preparing for Disaster for People with Disabilities and other Special Needs https://www.fema.gov/media-library/assets/documents/897

Neighboring Town Points of Contact for Non-Emergency Situations:

- Wallingford Police Dispatch: 203-294-2800
- Cheshire Police Dispatch: 203-271-5500
- Meriden Police Dispatch: 203-239-5321
- North Haven Police Dispatch: 203-239-5321

*Note: If a true medical or other type of emergency exists, Dial -911 for immediate assistance. Be sure to give your name and location and describe as best you can any medical symptoms related to your call for assistance.
Careful consideration is important, prior to enrolling, if participation is a goal.

There are several options for further advocacy issues. See contact information below.

- State of Connecticut 1-860-297-4300
- Center for Medicare Advocacy, Inc. 840-456-7790 or in Connecticut 800-262-4414
- State of Connecticut Office of Managed Care Ombudsman/Healthcare Advocate 1-866-466-4446

The Easter Seals Mobility Center provides thorough driving assessments to those who have an injury or impairment that may impact their ability to safely operate a motor vehicle. The Center provides a clinical assessment, an on the road assessment, as well as equipment recommendations and prescriptions.

McLean Driver Rehabilitation Program
Simsbury, CT
860-658-3700

Norwalk Hospital Driver Rehabilitation Program
Norwalk, CT
203-852-3400

CT DMV, make appointment with local DMV for evaluation. It requires an MD prescription to be cleared to take the test.

The NEAT Marketplace
Coventry and Holcomb Streets
Hartford, CT 06112
(866) 526-4492 toll free or (860) 243-2869
www.neatmarketplace.org

The NEAT Marketplace (New England Assistive Technology) restores donated assistive devices and medical equipment/supplies. NEAT is a demonstration center, as well as an equipment restoration center. Restored items are available for sale at reduced rates.
Assistance Dogs

East Coast Assistance Dogs Inc.
PO Box 251, Dobbs Ferry, NY 10522
914-693-0600
Info @ecad1.org
www.ECAD1.org

East Coast Assistance Dogs Inc. helps people with various disabilities gain greater independence through the use of specially trained dogs.

Mental Health and Substance Abuse

Federal
Substance Abuse & Mental Health Services Administration (SAMHSA) Samhsa.gov
Substance Abuse & Mental Health Services Administration, U.S. Department of Health and Human Services is a searchable directory of mental health, substance abuse, and support services treatment facilities.

Department of Mental Health and Addiction Services (DMHAS)
410 Capitol Avenue
Hartford, CT 06134
860-418-7000 ABI Wavier – Wise Program 866-548-0265

The Department of Mental Health and Addiction Services (DMHAS) promotes and administers comprehensive, recovery – orientated services in the areas of mental health, abuse prevention, and treatment throughout CT. DMHAS services adults over the age of 18 with psychiatric or substance abuse disorders, or both, who lack the financial means to afford services on their own. DMHAS provides a wide range of treatment including inpatient hospitalization, outpatient clinical services, 24 hour emergency care, day treatment, psychosocial and vocational rehabilitation, outreach services for persons with mental illness who are homeless, and comprehensive, community based mental health and support services. DMHAS provides a variety of treatment services to persons with substance abuse disorders, including ambulatory care, residential detoxification, long-term care, methadone or chemical maintenance, outpatient, partial hospitalization, and aftercare.

Services for HIV-infected include counseling, testing, support and coping therapies, alternative therapies, and co management. The department also provides prevention services, designed to promote health and wellness of individuals and communities. Also provides links to services in individual towns and cities, as well as ABI Waiver Services.

Employment

Department of Rehabilitation Services (DORS)
Includes BRS, (Bureau of Rehabilitation Services)
55 Farmington Ave, Hartford, CT 06105
Also has regional offices
1-800-537-2549
(860) 424-4844

The goal of the Vocational Rehabilitation (VR) Program is to assist individuals with significant physical and mental disabilities to prepare for, obtain, and maintain employment. Through the provision of individualized services, persons with disabilities who are eligible for vocational rehabilitation are supported in planning for and achieving their job goals. To be eligible, an individual must have a physical or mental condition which poses a substantial barrier to employment, and must require services in order to prepare for, find, and succeed in employment.

Ability Beyond
4 Berkshire Blvd.
Bethel, CT 06801
203-826-3072
abilitybeyond.org

Ability Beyond Disability’s mission is to enable individuals whose independent living skills are impaired by disability, illness, or injury, achieve and maintain self-reliance, fulfillment, and comfort, at home, at work, and in the community, by providing the best comprehensive home health and rehabilitation services. Also provides information and referral services.
Financial Assistance & Insurance Benefits

1-800-MEDICARE (1-800-633-4227)
MEDICARE.GOV

Medicare provides hospital insurance, medical insurance, and prescription drug coverage. Hospital insurance, sometimes called Part A, covers inpatient hospital care and certain follow-up care. Medical insurance, sometimes called Part B, pays for physicians’ services and some other services not covered by hospital insurance. Prescription drug coverage, sometimes called Part D, helps pay for medications doctors prescribe for treatment. Medical insurance and prescription drug coverage are optional, and you must pay monthly premiums. People who are 65 or older are automatically eligible for Medicare. Those who are determined to be disabled by the SSA are eligible after 2 years as long as certain other criteria are met.

The Social Security Administration www.socialsecurity.gov is responsible for two major programs that provide benefits based on disability: Social Security Disability Insurance (SSDI), which is based on prior work under Social Security, and Supplemental Security Income (SSI). Under SSI, payments are made on the basis of financial need. Social Security Disability Insurance (SSDI) is financed with Social Security taxes paid by workers, employers, and self-employed persons.

The Care Management Department can provide you with some assistance in this process or you can file for either program online.

Department of Social Services
55 Farmington Ave, Hartford, CT 06105
855-626-6632 www.ct.gov/dss

The Department of Social Services provides a broad range of services to the elderly, disabled, families, and individuals who need assistance in maintaining or achieving their full potential for self-direction, self-reliance and independent living. DSS administers over 90 authorized state programs.

MEDICAID (aka HUSKY) is health insurance coverage for low income &/or disabled residents of CT. Applications are processed by calling ACCESS HEALTH @ 855-805-4325, or on line at DSS www.connect.ct.gov, under ‘Apply for Benefits.’

The programs provide medical coverage assistance to low income persons. Services include health care services, medical care, out-patient services, doctor visits, homecare, and skilled nursing facilities, etc. Gaylord has a Benefits Liaison who can assist you with the application process. Your Care Manager can make a referral to the Benefits Liaison if that will be helpful to you.

Acquired Brain Injury (ABI) Waiver
Department of Social Services
55 Farmington Ave, Hartford, CT 06105
www.ct.gov/dss

This program is designed to provide a range of non-medical, home, and community based services to maintain adults who have an acquired brain injury (not a developmental or degenerative disorder), in the community. Adults must be age 18-64 to apply, must be able to participate in the development of a service plan in partnership with a Department social worker, or have a Conservator to do so, must meet all technical, procedural, and financial requirements of the Medicaid program, or the Medicaid for Employed Disabled program. An adult deemed eligible for the ABI Waiver, is the eligible for all Medicaid covered services. Application is made by completing an application form (found online), and returning a completed ABI Waiver Request Form.

Personal Care Assistant (PCA) Waiver
Department of Social Services
55 Farmington Ave, Hartford, CT 06105
www.ct.gov/dss

A Medicaid Waiver program that provides personal care assistance services included in a care plan to maintain adults with chronic, severe, and permanent disabilities, in the community. Without these services, the adult would otherwise require institutionalization.
The care plan is developed by a Department Social Worker in partnership with the adult. Adults must be age 18-64 to apply, must have significant need for hands on assistance with at least two activities of daily living (eating, bathing, dressing, transferring, toileting), must lack family and community supports to meet the need, and must meet financial requirements of the Medicaid program, or the Medicaid for Employed Disabled program. Eligible adults must be able to direct their own care and supervise private household employees, or have a Conservator to do so. An adult deemed eligible for the PCA Waiver, is eligible for all Medicaid covered services. Application is made by returning a completed PCA Waiver Request Form, which can be found on line.

‘Money Follows the Person’
Department of Social Services
55 Farmington Ave, Hartford, CT 06105
www.ct.gov/dss

‘Money Follows the Person’ is a program to assist people living in nursing homes or applying to them, the opportunity to live in their own homes in the community. This program works along with other state waiver programs. Information and the application process is found on line.

Connecticut Home Care Program for Elders (CHCPE)
Department of Social Services
55 Farmington Ave, Hartford, CT 06105  1-800-445-5394
www.ct.gov/dss

To be eligible, applicants must be 65 years of age or older, be a CT resident, be at risk of nursing home placement, and meet the program’s financial eligibility criteria. To be at risk of nursing home placement means that the applicant needs assistance with critical needs such as bathing, dressing, eating/meals, taking medications, and using the toilet. The CHCPE helps eligible clients continue living at home instead of going to a nursing home. Each applicant’s needs are reviewed to determine if the applicant may remain at home with the help of home care services.

Housing

The Care Management Department can provide you with the most recent booklet of listings/information on Section 8, HUD, and elderly housing. This is intended as a resource to you and your family for informational purposes or for future use. This department does not assist you in finding housing following your hospital stay.

Transportation Services

Public Transportation
Federal law requires that providers of mass transit services who receive federal financial assistance must certify that they provide people with disabilities full and equal access to the same services and accommodations as persons without disabilities. One of those services is public transportation. The U.S. Department of Transportation’s Urban Mass Transportation Administration (UMTA), the funding source, allows local areas to select one of a few acceptable options to meet that requirement. These options are:

1. The operators to ensure that at least 50% of the fixed route buses running during service hours are lift equipped.
2. The operator to establish a Paratransit or special system which is known as “door-to-door” or “dial a ride”, on a demand responsive basis.
3. The operator may establish service that is a combination of the other two options listed (1 and 2). Whenever a special service is employed, that service as a whole, must meet certain criteria of comparability with the service available to able-bodied persons.

Anyone who would like to use the ADA Paratransit services must be certified ADA Paratransit eligible. Information and/or an application can be obtained by contacting your local ADA Paratransit office.

CTRides.com provides a resource directory to local bus service and public transportation services by regional district.
Greater Bridgeport Transit Authority
www.gbtabus.com
203-333-3031
203-579-7777 – Paratransit

Estuary Transit District (Central Shoreline)
860-388-1611

Greater Hartford Transit
www.hartfordtransit.org
860-247-5329
860-724-5340

Greater New Haven Transit District
203-288-6282
203-288-6643 – Paratransit

My Ride of the Greater New Haven Transit District
840 Sherman Avenue
Hamden, CT 06514
203-288-6282
My Ride offers transportation for disable or elderly persons living in the South Central CT area.

Greater Waterbury Transit District
222.gwtd.org/index.htm
203-756-5550

Housatonic Area Regional Transit
www.hartct.org
203-748-2034
203-748-2511 – Paratransit

Middletown Transit District
860-346-0212
860-347-3313 – Paratransit

Northeastern Connecticut Transit District
860-774-3902

Northwestern Connecticut Transit District
860-489-2535

Norwalk Transit District
www.norwalktransit.com
203-852-0000
203-853-7465 – Paratransit

Southeast Area Transit District
860-886-2631
860-439-0062

Valley Transit District
www.invalley.org/vtd
203-735-6824
203-735-6408

Windham Region Transit District
www.wrtd.net
860-456-2223
860-456-1462 – Paratransit

If your transit provider discriminates against you, ask your operator for a copy of the UMTA certification. Check the UMTA certification with the State Office of Protection and Advocacy for Person with Disabilities – 1-800-842-7303.

Support Group
Gaylord Specialty Healthcare’s FAMILY & CAREGIVER SUPPORT GROUP of Acquired Brain Injury Patients
Runs first four Tuesdays of the month
Hooker 2 Solarium at Gaylord Hospital
4:30-5:30p.m.Open to all family and caregivers of current inpatients or recent Gaylord inpatients with an ABI.

Dorene Scolnic, LCSW
203-679-3506
Books

Where Is the Mango Princess? A Journey Back from Brain Injury
By Cathy Crimmins

Left Neglected
By Lisa Genova

Cracked: Recovering After Traumatic Brain Injury
By Lynsey Calderwood

Chicken Soup for the Soul: Recovering from Traumatic Brain Injuries:
101 Stories of Hope, Healing, and Hard Work
By Amy Newmark, Dr. Carolyn Roy-Bornstein, Lee Woodruff

I Am the Central Park Jogger: A Story of Hope and Possibility
By Trisha Meili

Over My Head: A Doctor's Own Story of Head Injury from the Inside
Looking Out
By Claudia Osborn

In an Instant: A Family's Journey of Love and Healing
By Lee and Bob Woodruff

Don't Leave Me This Way: Or When I Get Back on my Feet You'll Be Sorry
By Julia Fox Garrison

To Love What Is: A Marriage Transformed
By Alix Kates Shulman

Special acknowledgement to Dr. Glen Johnson for his support of Gaylord Specialty Healthcare using his book as the basis for our education manual. Please feel free to contact him at:

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(Web Site) www.tbiguide.com