# GAYLORD BRAIN INJURY EDUCATION MANUAL

AN EDUCATIONAL GUIDE FOR PATIENTS & CAREGIVERS



with excerpts from Dr. Glen Johnson Clinical Neuropsychologist Clinical Director of the Neuro-Recovery Head Injury Program Traverse City, MI

Gaylord Specialty Healthcare

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GAYLORD BRAIN INJURY EDUCATION MANUAL

The mission of Gaylord Specialty Healthcare is to enhance health, maximize function, and transform lives. Our organization lives our values daily: clinical excellence, compassion, integrity, respect, accountability and a commitment to safety. Our vision is to be a recognized and acknowledged destination for rehabilitation and complex medical care providing high quality, patient-centered, compassionate, team-based healing at every point in the journey from illness or injury to maximum recovery.

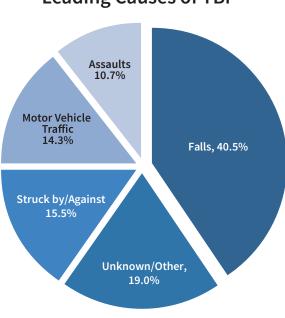
The Brain Injury Rehabilitation Program is one of the largest programs at Gaylord Specialty Healthcare. Rehabilitation after a brain injury is a shared effort. The brain injury survivor and their support system work together with the assistance of an interdisciplinary group of Gaylord professionals. 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.



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# What is a Brain Injury?



# Leading Causes of TBI

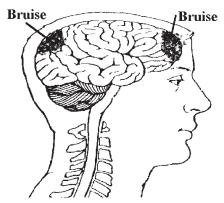
According to the CDC, each year the number of new cases of traumatic brain injury in the United States is approximately 2.8 million. It is estimated that up to 5.3 million Americans currently have a longterm or lifelong need for help to perform activities of daily living as a result a traumatic brain 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

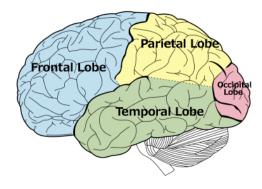
The brain receives information such as temperature, pain, and movement from the spinal cord which enters at the base of the brain. The spinal cord is like a thick phone cable with thousands of phone lines within carrying information up into the center of the brain and then branching out over its surface. 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.



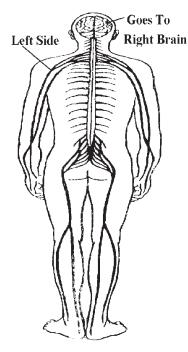
The left and right hemispheres of the brain are divided into four lobes: frontal, occipital, parietal, and temporal. The lobes on the right side have different functions than the lobes on the left side. The **frontal lobe** is the center of thinking and problem solving. The **occipital lobe** translates 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



Goes To<br/>Right BrainThe left temporal lobe is responsible for understanding<br/>language that is being heard, recognizing words, or<br/>putting words or pictures into categories. Because<br/>humans tend to think and express themselves in terms<br/>of language, the left temporal lobe is critical for day-to-<br/>day functioning.

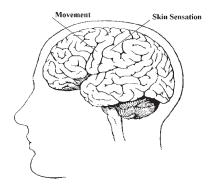
The **right temporal lobe** is responsible for processing musical information, identifying noises, localizing sound, communication without words, memory, and personality. If this area is damaged, it may be difficult to appreciate music, recognize a person, or stop talking.

#### 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.

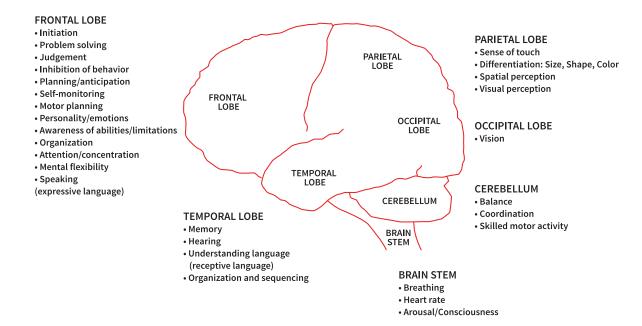
#### Planning, Organizing, and Controlling

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.

# **Simplified Brain-Behavior Relationships**



# **SECTION 2**

# Changes After a Brain Injury or Effects of Brain Injury

### 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. As a person recovers from their brain injury, there will be a change in the level of their arousal and alertness and there are different stages that you may see the person pass through.

#### Coma:

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. This appears as the deepest of deep sleep. 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.

**Helpful hint:** Stimulate your loved one's senses with smells, sounds, pictures, things to touch. Make sure to balance stimulation and rest beaks as this is really important for the healing brain.

#### Vegetative State:

In this stage, a person may demonstrate periods of wakefulness, however still do not demonstrate purposeful and reproducible movement to command. In this stage, the person is not really able to interact with their environment.

**Helpful hint:** Talk to your loved one even though they may not respond or fully understand what you are saying. Tell your loved one the day, date, time, where they are, and what has happened to them. It is best to limit conversing to one person at a time and continue to balance stimulation and rest breaks.

#### Minimally Conscious State:

In this stage, a person, inconsistently, may begin to follow simple commands, begin to verbalize, and/or begin interacting more purposefully with their environment.

**Helpful hint:** Limit the number of visitors at a time and for a day and speak in a calm tone. It can be helpful to ask your loved one to complete simple tasks (squeeze hand, blink eyes, stick out tongue) while making sure to give your loved one extra time to respond. Ask your loved one's therapy team for things you can do with them to help. Make sure to continue to balance stimulation with rest breaks.

Improvements with arousal can be slow and inconsistent. It is important to know that a person may not pass through all the stages and can stop at any one of them along the way. None of these early changes are necessarily predictable of what is to come, but instead indicate early signs of brain recovery.

Once someone has emerged from a minimally conscious state, they will not be renewed and fresh like in the movies or on TV, and in fact they still have work to do. However, they no longer have issues with arousal and alertness.

### **Cognitive Effects**

#### **Thinking**

A brain injury can cause changes with thinking, also known as cognition. The different areas of thinking 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.

Most people who have a severe traumatic brain injury experience some confusion after their injury. The confusion can last minutes, days, weeks or longer. 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 disorientated (i.e., not sure where he or she is, time of day, what has happened)

- Stare blankly, as in a "fog"
- Confuse times or tasks in his or her schedule of activities
- Mix up past or present events
- Make up convincing stories to fill memory gaps (this is called confabulation, discussed later in the memory section)

#### **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
- Frequently remind the brain injury survivor of correct details of past or present events
- Limit changes and provide structure in a daily routine

**Attention** is the ability to focus on something and process it, and 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 common for a person with a severe brain injury to only be able to pay attention to a task for a few seconds or a few minutes at a time. 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 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

**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. 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"
- Practice organization skills early in the day. Fatigue will worsen the ability to organize

**Memory** is the ability to learn, keep, and use information. Impaired memory is a common problem after a brain injury. There are many different types of memory and terms related to it. Most commonly, **short-term memory** is information that is stored for a few seconds to a few minutes, and **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.

Several different areas of the brain are responsible for memory processes. Processes related to memory include **encoding** of new information, **storage** of information for later use, and **retrieval** for when the stored information is needed.

Also after a brain injury, new issues with memory may occur. **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 a brain injury. 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 brain injury. Patients who have had a long hospital stay, may only be able to recall the last portion of their stay. **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.

#### 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 other way to improve memory. Compensation is the use of internal and external strategies as a substitution for lost functions. 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.

### **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 (**receptive language**), and/or the ability to express oneself through talking or writing (**expressive language**). 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 (**word finding deficits**), 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 healthcare providers will evaluate the specific communication areas that are affected. Feedback is important to help improve a person's communication. The following examples outline some common communication effects from a brain injury and helpful hints.

#### Issues with Receptive Language and Helpful Hints:

- Difficulty paying attention to what is said
  - Get his or her attention before speaking
  - Reduce distractions
  - Reduce the rate of speech and pause frequently to allow the person with a brain injury time to process and respond

- Misinterpreting what is said
  - Be clear and to the point, keep it simple
  - Periodically stop and ask to restate what was heard
- Being "off topic" compared to the rest of the people in the conversation
  - Avoid abrupt topic changes
  - In group conversations, help set a slower pace of conversation
- Problems understanding what is read
  - Review reading material, using the 5W strategy Who, What, Where,
     When, Why
- Trouble stating the main idea or main point
  - Emphasize important information in the text

#### Issues with Expressive Language and Helpful Hints:

- Problems finding the right word to describe what he or she is trying to say
  - $\circ$  Give the person time to locate the word he or she is looking for
  - Encourage him or her to use another word that is close in meaning or use many words (or a description) instead of using a single word i.e. if the a person cannot come up the word "belt" he may say "the thing that holds up pants"
- Unable to start or is slow to start conversations
  - Ask a leading or open-ended question such as, "What do you think about....?"
  - $\circ$  Reinforce all efforts to start or contribute to a conversation
- Problems explaining what he or she means
  - Provide the person with time to organize his or her thoughts
- Bringing up the same topic over and over again (called perseveration)
  - Use redirection if necessary

- Monopolizing a conversation
  - Politely interrupt and ask for a chance to speak
  - Develop a hand signal which indicates that they may be monopolizing the conversation
  - Use positive reinforcement for all attempts at listening rather than talking
- Using body language or facial expressions that doesn't "match" what is being said
  - Tell the person with a brain injury that you are confused by the difference in body language and spoken message
- Standing too close or too far from the speaker or making uncomfortable physical contact
  - $\circ$  Politely ask the person to stand closer or further away
  - $\circ$  Decide on a signal to indicate problematic behavior
- Having poor eye contact or staring at others during conversation
  - Give feedback on the right amount of eye contact to keep with another person
  - Explain the behavior is making you feel uncomfortable

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.

#### **Issues with Speech Production: Dysarthria**

**Dysarthria** means having a hard time using the muscles needed to form words and produce sounds.

What might be seen:

- Slow, slurred, or garbled speech
- Speaking too loudly or softly
- Speaking too rapidly

#### Helpful Hints:

- Allow ample time for the person to express him or herself
- Encourage them to speak slowly and exaggerate mouth movements when saying a word
- 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)
- 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
- Have the person watch your mouth to copy a sound or word

#### **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, vision, and swallowing.

#### **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/tetraparesis**.

#### **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 healthcare provider, 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 healthcare provider 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 common. 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 numbress 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**

One of the most common complaints after a traumatic brain injury is change in vision. This is because there is often a miscommunication between the brain and the eyes. Sometimes the eyes do not work well as a team after injury. Some muscles in the eye may be weak (and make the eyes appear misaligned). This may make the patient feel like there is persistent blurry or double vision. A Patient can also be missing a part of their visual field or not seeing "the whole picture". Lastly, with more blunt trauma, blindness may occur. Like other effects of traumatic brain injury, visual problems may improve with time as the brain recovers. For long term solutions a healthcare provider may need to consult a special healthcare provider, such as a neuro-optometrist to help.

Here are some of most common visual problems:

**Double Vision:** Three major nerve from the brain stem control eye movements. If any of these are impacted by the brain injury the eye muscles may not work perfectly as a team and the person may see double.

**Field Cut:** After an injury to the brain a person can have a vision field cut. This means that a portion of each eye does not perceive vision. Missing vision from half of each eye is also **hemianopsia**, while a quarter of a field loss is called a **quadrantopia**. This does not mean they see black in the missing areas, but the brain does not recognize it is there, much like the space behind our head. These field cuts are from injury to the brain and not the eyes. This may distort where middle is perceived.

#### 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

### **Medical Effects**

#### **Bowel and Bladder**

Problems related to bowel and bladder function are common and 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 healthcare provider 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 compression boots, and/or 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 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.

#### What is fatigue?

Fatigue is a feeling of exhaustion, tiredness, weariness or lack of energy. After TBI, you may have more than one kind of fatigue:

- 1. Physical fatigue: "I'm tired and I need to rest. I'm dragging today."
- 2. Psychological fatigue: "I just can't get motivated to do anything. Being depressed wears me out; I just don't feel like doing anything."
- 3. Mental fatigue: "After a while, I just can't concentrate anymore. It's hard to stay focused. My mind goes blank."

#### Why is fatigue important?

When you are fatigued, you are less able to think clearly or do physical activities. If you are overwhelmed by fatigue, you have less energy to care for yourself or do things you enjoy. Fatigue can have a negative effect on your mood, physical functioning, attention, concentration, memory and communication. It can interfere with your ability to work or enjoy leisure activities. It can make activities such as driving dangerous.

#### How common is fatigue after TBI?

Fatigue is one of the most common problems people have after a traumatic brain injury. As many as 70% of survivors of TBI complain of mental fatigue.

#### What causes fatigue?

Fatigue is normal for anyone after hard work or a long day. In persons with TBI, fatigue often occurs more quickly and frequently than it does in the general population.

The cause of fatigue after TBI is not clear but may be due to the extra effort and attention it takes to do even simple activities such as walking or talking clearly. Brain function may be less "efficient" than before the injury.

- **Physical fatigue** can come from muscle weakness. The body needs to work harder to do things that were easy before the TBI. Physical fatigue gets worse in the evening and is better after a good night's sleep. Often this kind of fatigue will lessen as the individual gets stronger, more active and back to his or her old life.
- **Psychological fatigue** is associated with depression, anxiety and other psychological conditions. This type of fatigue gets worse with stress. Sleep may not help at all, and the fatigue is often at its worst when you wake up in the morning.
- **Mental fatigue** comes from the extra effort it takes to think after your brain is injured. Many common tasks take much more concentration than they did before. Working harder to think and stay focused can make you mentally tired.

#### • Certain conditions are known to cause or increase fatigue:

- o Depression
- o Sleep problems, such as sleep apnea
- o Seasonal allergies
- o Hypothyroidism or other endocrine gland disorders
- o Respiratory or cardiac problems
- o Headaches
- o Lack of physical exercise
- o Vitamin deficiency/poor nutrition
- o Stress
- o Low red blood cell counts (anemia)
- o Medications commonly used after TBI, such as muscle relaxers and pain medication

#### What can be done to decrease fatigue?

- Pay attention to what triggers your fatigue, and learn to identify the early signs of fatigue, such as becoming more irritable or distracted. Stop an activity before getting tired.
- Get more sleep and rest. If you have insomnia, tell your doctor. There may be a medical condition causing this, or there may be useful treatments.
- Set a regular schedule of going to bed and awakening the same time every day: your body and mind will be more efficient. Include some regular rest breaks or naps. Be careful to limit naps to 30 minutes and avoid evening naps.

- Alcohol and marijuana will generally make fatigue worse.
- Caffeine (coffee, cola products) should be avoided after lunch if sleeping is a problem
- Resume activities gradually, over weeks or even months.
- Start with familiar tasks at home or work that you can complete without fatigue. Gradually increase the complexity of each task, taking breaks as needed.
- Improve your time management:
  - o Plan and follow a daily schedule. Using a calendar or planner can help manage mental fatigue.
  - o Prioritize activities. Finish what is most important first
  - o Do things that require the most physical or mental effort earlier in the day, when you are fresher.
  - o Avoid over-scheduling.
  - o If visitors make you tired, limit time with them.
- Exercise daily. Research has shown that people with TBI who exercise have better mental function and alertness. Over time, exercise and being more active helps lessen physical and mental fatigue and builds stamina. It also may decrease depression and improve sleep.
- Talk to your doctor:
  - o Discuss medical or physical problems that may be causing fatigue.
  - o Have your doctor review all your current medications.
  - o Tell your doctor if you think you might be depressed so treatment can be started.
  - o Ask your doctor if there are any blood tests that could help to find out what is causing your fatigue.

#### Source

#### Authorship

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#### 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.

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.

#### **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.

#### 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:

**Focal 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 accidently 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 may include review of medications, blood tests, and imaging studies of the brain which include 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. Treatment for potential seizures and seizure disorders come in two forms- short term and long term. Seizure prophylaxis, or use of AEDs (antiepileptic 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. Long-term use of preventative medication is not recommended. 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.

#### **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.

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 healthcare provider 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.

### **Emotional Effects**

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.

# SECTION 3 The Continuum of Care for Brain Injury

## 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 (Physiatry) or Internal Medicine. Since patients have survived a very severe and, in many cases, life threatening illness, continued management of medical complications beyond the acute care hospital is essential. Without medical stability, the brain injury survivor's full participation in a rehabilitation program

would be impossible. The physician will assess many aspects of the ongoing health care needs of the brain injury survivor. 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 a nurse practitioner (APRN), both of whom play key roles in managing the brain injury survivor's ongoing health care needs.

# **Nursing:**



A registered nurse is responsible for establishing a plan of care based on the needs of the patient as identified by the nurse. The ultimate goal of rehabilitation nursing care is helping people regain the control of and the responsibility for their lives. It is important to remember that the focus is on the brain injury survivor 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. Monitoring the person to prevent or correct problems such as skin pressure areas, infection, deformities and excess weight is very important. Physical, cognitive, social and emotional reactions are also observed and recorded. Rehabilitation nurses work closely with other team members in evaluating and helping the brain injury survivor practice on the unit the functional skills taught in other therapies. They address bowel and bladder training as needed. Because the family is part of the team, education and participation in their relative's care is necessary. Correct techniques are taught to the family in the therapy departments and on the nursing unit. Once these techniques are learned, the family will be encouraged to help whenever they are present. Adequate family training not only makes the transition from hospital to home possible but often can mean the difference between the stroke survivor being able to go home or to another facility.

### Food and Nutrition:

A Registered Dietitian Nutritionist (RDN), upon nutrition consultation, will evaluate and monitor the nutritional status of brain injury survivors and provide guidance for the person, family and team. Interventions may include education about healthy food choices to help manage chronic health conditions and assistance with managing poor appetite or addition of nutrition supplements. The dietitian also assesses and may modify a tube feeding regimen as needed. The RDN works closely with the Speech-Language Pathologist (SLP) when a modified consistency diet is needed due to swallowing problems. A representative from the Food & Nutrition department meets with inpatients daily for individual menu selections.

Before changing the diet or taking any type of supplement, one should always check with their health care provider. Nutrition education may be provided in both group and individual sessions. Continued nutrition support and counseling may be recommended after discharge on an outpatient basis.

### **Occupational Therapy:**



The occupational therapist (OT) evaluates and treats areas which effect a person's ability to care for his or her self. The role of the occupational therapist 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, ability to get to and

from the bathroom, and preparing meals. A brain injury may cause temporary or permanent weakness or paralysis on one side of the body. A person may need to re-learn how to perform these activities with the use of one arm or leg, and to compensate for visual, perceptual, and cognitive deficits. The occupational therapist may recommend adaptive equipment or modify the environment to assist the brain injury survivor with their ability to perform these tasks more independently. The occupational therapist also provides demonstrations and training to family members in the areas of self care and mobility in preparation for a safe discharge home.

### **Physical Therapy:**



The role of the physical therapist (PT) is to assist brain injury survivors in attaining the highest level of mobility possible following a brain injury. The physical therapist will conduct an evaluation of movement in both legs comparing strength, sensation, tone and coordination, often which may be impacted following a brain injury.

The therapist will also evaluate endurance, balance, as well as important mobility skills necessary for getting out of bed to walk, move from/to a bed or wheelchair ("transfer"), or use 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 to a brain injury survivor's recovery following a brain injury. In consideration of a brain injury survivor/family goal for a discharge to home, it may be advised for the appropriate family members to attend treatment sessions for training to assist the patient with safe mobility in the home environment. Recommendations for necessary assistive equipment and continued therapy services are made by the physical therapist prior to discharge.

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

### **Respiratory:**



The Respiratory Therapist (RT) plays a key role in the management of the brain injury patient. 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

stroke survivor's care. The Respiratory Therapist works with members of the interdisciplinary team to facilitate ambulation as soon as appropriate and aid in recovery and return to everyday activities. The RT staff will also provide education on breathing interventions to maintain optimal respiratory function.

### **Speech-Language Pathology:**



If appropriate, brain injury survivors in the inpatient program are evaluated by a speech-language pathologist (SLP). The doctor will order an evaluation of swallowing, communication and/ or cognition (See each specific section for more information). Following the evaluation(s), an individualized treatment plan is developed. Goals are set by the

brain injury survivor, family members or therapist, to assist with return to the highest level of function. Examples of speech therapy goals include: returning a patient to eating the least restrictive diet if he is nothing by mouth (NPO) or on a modified diet, 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 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. Therapeutic Recreation 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 one to discover new and exciting activities through interest exploration and to re-familiarize one with their community. Leisure Education also helps an individual continue to participate in activities of interest through adaptive equipment.

### **Care Management:**

The Care Manager coordinates health care services that a person with a brain injury requires through a collaborative multi-disciplinary team approach. It is the responsibility of the Care Manager to provide education and support to the person and their family as well as to hospital staff regarding community resources, managed care issues, or payment / payer issues.

Discharge planning is initiated upon 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 a plan. It is the role of the Care Manager to ensure that the brain injury survivor's plan of care promotes a safe and timely discharge, and to evaluate the overall plan for effectiveness. The Care Manager involves both the brain injury survivor and family in the formulation of goals for a safe discharge. The Care Manager provides the link between provider and payer organizations, physicians and the community in the transition of your care through the health care continuum.

### **Psychology:**

The role of Psychology for patients admitted to the inpatient rehabilitation program, and their families, is to provide an evaluation of current functioning, including emotional, personality, cognitive and behavioral. In addition, the clinician will assess one's adjustment to illness. Recommendations are offered to guide treatment. Psychological treatment may include individual, family and/or group therapies to aid in adjustment issues and coping for the brain injury survivor and family members. Treatment would include collaboration with other care providers to ensure continuity of care.

A brief neuropsychological evaluation may also be conducted based upon need with the goal of helping to inform treatment as well as the brain injury survivor and family understanding of the cognitive and emotional changes. Upon discharge, resource information may be provided for follow-up as necessary. After discharge, the role of Psychology for brain injury survivors may continue to the outpatient rehabilitation program and include an assessment by a neuropsychologist or other clinician. This is done to guide treatment and collaborate with outpatient doctors, physical/occupational and/or speech therapists to ensure continuity of care and to ensure the person's needs are met. Psychology facilitates outpatient individual and group therapies. Neuropsychological evaluations may also be conducted based upon individual need, to further inform treatment, especially as individuals begin to resume premorbid life roles (e.g. academia, employment) or seek additional services in the home. Resource information is also provided to help the brain injury survivor reconnect with his/her community and bolster his/her support network.

### **Chaplaincy Services:**

Chaplains serve to enhance health, maximize function and transform lives by helping patients, family members and staff draw upon their own religiosity and spirituality as potential sources of healing and comfort. We support patients, family members and staff of all faith backgrounds.

### 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.

### **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 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 how 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.

### **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, brain injury survivors can discharge home with home care or 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 often then discharge to outpatient therapy. Other times, people with brain injury can also 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 persons with a brain injury on the Wallingford campus.

### **Outpatient Medical Services:**

The Outpatient Medical Services Department at Gaylord Hospital provides medical evaluations and follow-up. The Outpatient Medical Services Department is staffed with physiatrists who are skilled in the treatment of individuals with stroke. Gaylord physiatrists can prescribe specialized treatments for spasticity management. In addition, wheelchair accessible GYN services and urology consultations are offered at Gaylord.

### **Outpatient Therapy Services:**

Outpatient therapy services are typically provided to you when you are living in your home environment and can attend therapy outside of your home. The Outpatient Therapy Department at Gaylord Hospital provides physical therapy, occupational therapy and speech therapy services. Gaylord's Outpatient Therapy Department is staffed with therapists who are skilled in a broad range of diagnoses including BI, Stoke, MS, Parkinson's, SCI and vestibular disorders.

### **Outpatient Psychology Services:**

The Psychology Department offers short-term, evidence-based, cognitivebehavorial counseling services with a focus on helping people adjust to catastrophic injury (TBI, stroke, spinal cord injury) and related issues including substance abuse, PTSD, chronic pain, and general mental health concerns.

### Additional Services:

Nutrition consultations are also performed in Gaylord Outpatient Services. (203) 284-2888, Appointments, option 1

# **SECTION 4**

# Gaylord Specialty Healthcare Programs and Services

### **Community Re-Entry:**

Community Re-Entry is a group session provided at Gaylord Hospital. Patients participating in community re-entry are able to participate in planning and completing a trip to a community location (restaurant, museum, grocery store, etc.) with therapy staff and peers. The purpose of community re-entry is to provide an opportunity for exposure to community barriers, increase knowledge of leisure resources in the community, increase skill building through on-site therapy intervention, provide opportunity for social interaction and increase physical and/or cognitive functioning.

### **Transitional Living:**



The Louis D. Traurig House is the only transitional living center for people with acquired brain injuries in Connecticut. Located in Wallingford on the campus of Gaylord Hospital, 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 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. 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. Each resident also spends weekends home to utilize their skills with their loved ones in their own home. The length of stay is modified to meet the needs of each resident, typically between 4-6 weeks.

They also receive services in our Cognitive or Aphasia Day Treatment Program, at Gaylord Hospital; such as cognitive retraining, communication skills, community re-entry, psychosocial skills, independent living skills, psychological support as well as individual Physical Therapy, Occupational Therapy and Speech Therapy. Insurances are accepted with a contract for transitional living are: Blue Cross of Connecticut, Connecticare, Medicaid, and Workman's Comp. Unfortunately, some insurances like Medicare, United and Cigna do not have a benefit. Please talk with your case manager for any inquiries about acceptance into the transitional living program.

The Traurig House allows each individual and their family to "practice" what it will be like upon returning home. You and your family are welcome to visit for a tour by calling (203) 741-3488 or (203) 284-2773.

### **Orthotics and Prosthetics Clinic:**

If you have bracing or splinting needs, Gaylord's Orthotics and Prosthetics Clinic can help. Gaylord's weekly brace clinic offers appointments with a team of a Gaylord physiatrist (a board certified physician of Physical Medicine and Rehabilitation), a physical therapist and an orthotic vendor. Each member of this team is experienced in assessing and fitting braces and splints to restore and promote function, increase range of motion, provide proper positioning, improve transfers, standing and walking. Our expert staff partners with cutting edge vendors who collaborate on the latest technology options.

Whether you experienced a brain injury a few months ago, or many years ago, having a team of experts evaluate your present bracing and splinting needs is important. Uncompensated gait patterns may lead to changes in function which may cause orthopedic or neuromuscular problems. Painful and stiff hands can impede function. Whether you need an assessment of your current brace or splint, or are interested in new technology, we can help you.

### Wheelchair Assessment Service:

An optimally prescribed wheelchair and seating system can help a wheelchair user achieve independence and wellness. Gaylord's Wheelchair Assessment Service (WAS) evaluates clients for mobility devices, including manual wheelchairs, scooters, power wheelchairs, as well as custom seat cushions and back supports. A WAS appointment consists of a comprehensive evaluation by a physical therapist who is a certified Assistive Technology Professional (ATP) with advanced training in seating and positioning.



Rehab Technology Suppliers are present at evaluations to assist in equipment selection and to provide the equipment to a wheelchair user. A comprehensive evaluation is completed to address your seating and mobility system needs. Extensive equipment simulation is performed to assist you in equipment selection. Gaylord WAS clinicians work closely with equipment manufacturers to ensure that a wide variety of state-of-the-art equipment options are available for trial. Additional services include pressure mapping assessments, standing frame evaluations, custom molded seat cushion and back support

fabrication.

### **Aquatic Therapy Program:**



Aquatic therapy, therapeutic exercise in warm water, provides a soothing, efficient method for achieving movement. Therapy in water offers a cushioning environment for those with various stroke related issues, since the physical properties of water diminish the effects of gravity. Gaylord's Aquatic therapy program provides treatment by registered physical and occupational therapists

with advanced training in aquatic therapy techniques. The ability to swim is not necessary to participate. Aquatic therapy can offer many benefits, including increased ability to stand and walk in the water, greater flexibility, balance and strength building, pain reduction and relaxation.

Gaylord's pool is maintained at a therapeutic temperature of 90 degrees. The state-of-theart 75- by 25- foot therapeutic pool is specially designed for people with disabilities. The unique pool is equipped with various ways to enter the water such as stairs, a hydraulic lift, and a ceiling lift to accommodate bariatric patients. Gaylord also offers Aquacize, a community aquatic exercise program for independent use of the pool during designated hours.



#### The following conditions would prohibit participation in Aquatic Therapy:

- Open wounds
- Bowel incontinence
- Bladder incontinence
- Urinary Tract Infection in initial stages
- Uncontrolled seizures
- Isolation precautions
- Skin infections
- Fever
- Tracheostomy

If you are interested in Aquatic Therapy, discuss if it is an appropriate exercise method with your physician and therapist.

### **Day Treatment Programs:**

Gaylord offers the **Cognitive Day Treatment Program** and the **Aphasia Day Treatment Program**. After a brain injury, you may experience a variety of cognitive deficits or communication deficits. If you are having difficulty with orientation, attention, memory, reasoning, problem solving, executive functioning or pragmatics, Gaylord's Cognitive Day Treatment Program may be for you. If you observe problems with auditory comprehension, verbal expression, reading or writing, Gaylord's Aphasia Day Treatment program could help you. These specialized and unique programs are intensive, full day individualized programs that include a mix of group and individual therapies. Since family members are important to your recovery, they are encouraged to take an active role. Our specialists will design a treatment plan based on each individual's specific needs.

## **SECTION 5**

### **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.

# **SECTION 6**

# Beyond Gaylord—Tips for a Successful Life

### **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 (selfawareness) 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 heighten 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 preinjury activities and settings. 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.

### Driving

To some, driving is considered a rite of passage; a form of independence. However, the effects of strokes can significantly impact a person's ability to drive. Therapists will help address those deficits and skills during your course of treatment. Your therapist and primary care provider will help determine if and when you're ready to resume driving and will provide you with the information required to get the process started.

### 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:

- Arts and crafts
- Baking
- Bird watching
- Collecting
- Cooking
- Crossword puzzles
- Exercising
- Games
- Gardening
- Jigsaw puzzles

- Movies
- Music (listening to or playing)
- Reading
- Socializing
- Sports
- Sudoku
- Technology
- Trivia
- Word searches
- Writing

### The Creative Expressions Program at Gaylord Hospital

Developed and coordinated through the Therapeutic Recreation Department, the Creative Expressions Program offers patients and people in the community with disabilities an opportunity to use art as therapy and as a creative outlet. Participants will work with peers and staff alike to enhance their painting skills. Participants must be able to work independently, have their own transportation, and be independent with personal care needs. Participants may be returning to art as an interest or trying it for the first time. If interested, please contact at 203-284-2732.



### **Sports Association**

The Gaylord Sports Association provides adaptive sports and recreation opportunities for persons with physical disabilities such as spinal cord injuries, strokes, amputations, traumatic brain injuries,

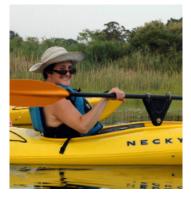
pulmonary disorders and visual impairments. We believe that everyone, regardless of ability level, should have the opportunity to enjoy sports and recreation. We work with our participants on an individual basis to help them achieve their adaptive sports goals, whether it is to try a new activity, return to a past leisure pursuit or strive to become a Paralympic athlete. We offer the most diverse adaptive sports program in the state of Connecticut, with over a dozen different sports, ranging from introductory recreation activities to highly competitive sports teams. Our goal is to assist participants in gaining the confidence, independence and skills to meet their adaptive sports goals. Opportunities to get involved in adaptive sports include introductory clinics, discovery nights, clubs, classes, competitive teams and veteran specific programs. The Sports Association is a chapter member of Disabled Sports USA and a Bronze Level Paralympic Sports Club. Examples of sports offered are:

- Rock Climbing
- Downhill Skiing
- Sled Hockey
- Wheelchair Tennis
- Paratriathlon
- Water Skiing
- Yoga

- Archery
- Cycling
- Boccia
- Golf
- Kayaking
- Wheelchair Rugby
- Veteran's Fishing







# 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
- Carpeting
- 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**

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

### **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**

o Install night lights, or light switch within reach of bed

o Place telephone within reach of bed

- o Raise or lower bed height as needed
- o Arrange furniture for easy maneuvering

#### 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**

- o Install grab bars where needed
- o Provide non-skid mats and night lights
- o 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**

o Store items on reachable shelves (between person's eye and hip level)

### **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.

#### **Resources:**

**1.** Connecticut Red Cross, 209 Farmington Ave. Farmington, CT 06032 877-287-3327 http://www.redcross.org/local/connecticut

**2.** Prepare my family for a Disaster, U.S. Department of Homeland Security https://www.dhs.gov/how-do-i/prepare-my-family-disaster

**3.** Disaster Resources for People with Disabilities and Others with Access and Functional Needs, Emergency Managers & Planners & Disability-focused Organizations http://www.jik.com/disaster.html

**4.** Ready.gov Prepare, Plan, Stay Informed: Individuals with Disabilities and Others with Access and Functional Needs https://www.ready.gov/individuals-access-functional-needs

**5.** FEMA: Preparing Makes Sense for People with Disabilities, Others with Access and Functional Needs, and the Whole Community https://www.fema.gov/media-library-data/1440775166124-c0fadbb53eb55116746e811f258efb10/FEMA-ReadySpNeeds\_web\_v3.pdf

**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.

### 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.brain injury.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.

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

**Technology and Equipment** 

### Augmentative and Alternative Communication:

**Augmentative and alternative communication** (AAC) incorporates the communication methods 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 express his or her own feelings, thoughts, wants and needs.

A team approach is utilized when providing AAC services. A Speech-Language Pathologist will identify the need for AAC and 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 use. An occupational therapist will determine most effective ways to access communication aides and a physical therapist to 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. Assistive technology can be off the shelf, modified or customized. Assistive technology enables a stroke survivor 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 assistive technology 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. Assistive technology also includes devices that increase your mobility, computer access and communication. Assistive technology 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. Therapists work with both the brain injury survivor and the family to determine specific goals and objectives. Therapists are able to evaluate skill levels and make recommendations as appropriate. Assistive technology also includes making adaptations to existing equipment to increase the level of function. During the brain injury victim's inpatient stay, 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 brain injury survivor with a number of resources and trial assistive technology products if appropriate.

### What Does Gaylord Have:

#### **Ekso**<sup>TM</sup>



Ekso<sup>™</sup> 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.



### **Functional Electrical Stimulation** (FES)

Electrical stimulation is the clinical use of 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.

#### Standing Frame/Tilt Table



A standing frame/tilt table is a device that allows the brain injury survivor to be supported in a standing position if they have weakness in the torso and legs. Regular use of a standing frame/tilt table may 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<sup>TM</sup>



The Lite Gait<sup>™</sup> is a weight supported harness system that is used in therapy to assist brain injury survivors that have difficulty standing and walking.

#### Walk Aide™



The Walk Aide<sup>™</sup> is a device to help prevent "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<sup>™</sup> is a device that assists in providing electrical stimulation to help strengthen the weak muscles that

make it hard to pull the foot up. The physical therapist can discuss and make recommendations as to whether or not the Walk Aide<sup>™</sup> device will help with recovery.

### Apple iPad®



The Apple iPad® is used to provide assistance with communication and organization. Patients are taught to use applications that help with cognitive and functional capabilities. With this technology patients can Skype<sup>™</sup> and keep in touch with family and friends. Our staff helps patients to use the best apps to maximize their time and effort.

#### **Bioness Integrated Therapy System - BITS**®



BITS is a multi-disciplinary therapy solution designed to motivate patients and improve clinician efficiency. With 24 unique programs and four standardized assessments, BITS' interactive touchscreen and diverse program options challenge patients through the use of visual motor activities, visual and auditory processing, cognitive skills and endurance training.

#### ZeroG<sup>®</sup> Gait & Balance System<sup>®</sup>



The ZeroG Gait and Balance System protects patients from falls while providing dynamic body-weight support as patients practice walking, balance tasks, sit-to-stand maneuvers and even stairs. Because ZeroG is mounted to an overhead track, there are no barriers between the patient and therapist. With the only ZeroG in Connecticut, inpatients can begin rehabilitation as early as possible in a safe, controlled environment.

### AlterG<sup>®</sup> Anti-Gravity Treadmill<sup>®</sup>



AlterG Anti-Gravity Treadmills use NASA-developed Differential Air Pressure (DAP) technology that enables unprecedented unweighting therapy and training capabilities. This unique unweighting with air pressure comfortably lifts the user and allows him/her to walk or run at a fraction of their body weight. Gaylord has AlterG treadmills in all outpatient locations - Cheshire, North Haven and Wallingford.

#### Kinesiq



The first balance and motor capacity exercise equipment dedicated to physical and neurological rehabilitation as well as to preservation of functional autonomy. It combines two motion platforms in perfect synchronization with multimedia content for passive and assisted movements. The program types are: weight shift and movement exercises, a "games: program requiring different movements that can be used for evaluation and comparison testing requiring vision, cognition and motor planning, and also multimedia balance platform activities.

What scenarios does it feature?

- Play balance games to restore everyday abilities
- Take a bus or a subway ride
- Dance with rhythm on Latin tunes
- Ride a gondola in Venice or sail thru Caribbean Sea

#### Synchrony



Synchrony is an interactive sEMG Dysphagia Treatment System. Unlike any other dysphagia rehabilitation solutions available, Synchrony is designed specifically for you and your speech language pathologists (SLPs) to visualize swallow activity using virtual reality sEMG (surface

electromyography) biofeedback. With engaging exercise visualizations, data dashboards, and reporting tools, this technology gives SLPs more power than ever to help you to learn new behaviors which will enhance your quality of life.

#### Saebo MyoTrac Infiniti®



The Saebo MyoTrac Infiniti® is a comprehensive, portable biofeedback electrical stimulation system that delivers stimulation to the targeted muscles based on the client's very own EMG signal. This combination of biofeedback and stimulation provides a unique opportunity for people to maximize their rehabilitation and recovery.

#### **Brake Reaction Test**



The Vericom Response is a tool specifically designed to be used by Occupational Therapists, Medical Professionals, Research Teams, and Driver Training providers to test human perception and reaction time. It consists of software, a steering-wheel, and accelerator/brake pedal system, designed for use in an office type setting in front of a computer

mounted to a desk with the accelerator/brake pedals on the floor. The Vericom Response includes 10 preloaded driving videos that simulate driving in the city, around mountain curves, rain, snow, and a 2-lane highway as primary distractions. The user can select from 9 different objects that will enter the video as a "stimulus" that the client is instructed to react to. The client provides the response and input via a steering-wheel/pedal hardware system that connected to the PC operating the Response software. Upon conclusion of each test session, the results table is automatically displayed for review.

#### Helix HD



Helix HD is a compact, portable & lightweight HD video magnifier. The Helix HD plugs directly into your HDTV or HD computer monitor and is controlled via a wireless control pad. The Helix HD has a wide viewing area (up to 8 inches) and allows full page width magnification of any text or images up to 150x.

#### Virtual Reality



The Vive is a virtual reality system used to immerse a patient into a new world. Patients can choose their experience- archery, guided meditation or exploring the world are all options. Benefits include helping the patient work on functional skills such as balance or physical skills through sports or movement, coping and adjustment to the disability or returning to a career through simulation. Experiences can be guided by a therapist and experienced from a seated or standing position.

#### Sesame Enable



Sesame Enable is a hands free and touch free application that can be installed on any android device from 7.0 and above, including smart phones and tablets. It allows the user complete control over the device through head movements which controls the curser. The application is able to be customized based on the users level of ability including but not limited to tremors,

decreased neck range of motion, decreased strength and hemiplegia. It is ideal for people living with paralysis or upper extremity impairments - Spinal Cord Injuries, Multiple Sclerosis, Lou Gehrig's disease (ALS), Cerebral Palsy, and other conditions. This technology when combined with other smart devices such as environmental control units allows the user access and control of their home environment increasing independence and quality of life.

#### Bioness<sup>TM</sup> and MYOMO<sup>TM</sup>

Gaylord has two devices specifically designed to be utilized with persons who have weakness in one or both of their arms following a brain injury. The BIONESS<sup>TM</sup> and the MYOMO<sup>TM</sup> are both robotic devices that the therapist may utilize during treatment as indicated.



The MYOMO<sup>™</sup> is an FDA-approved device for use with individuals who have had a stroke and have left over arm weakness. The MYOMO<sup>™</sup> is designed to improve arm function and increase independence in persons following a brain injury. The device allows brain injury survivors to initiate and control movement in a weakened arm. The use of the device is non-invasive and does not involve electrical stimulation of the muscle.



Gaylord also has Bioness H200 Wireless Therapy<sup>™</sup> 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, reeducating muscles, maintaining and increasing range of motion, increasing local blood circulation, and reducing muscle spasm. The occupational therapist 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 your clinician to stimulate the appropriate nerves and muscles in your leg to lift your foot, stabilize your knee and help with a more natural walking pattern.

## **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 buttock/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<sup>™</sup> 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.

### Resources

Americans with Disabilities Act www.ADA.gov The ADA website provides information

The ADA website provides information and technical assistance regarding the Americans with Disabilities Act.

1-800-514-0301 (voice) 1-800-514-0383 (TTY)

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.

Easter Seals Mobility Center 158 State Street Meriden, CT 06450 (203) 237-7835 www.cteasterseals.com

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.

East Coast Assistance Dogs Inc. P.O. Box 831 Torrington, CT 06790 (860) 489-6550 ECAD1@aol.com 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**

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 TF 800-446-7348 860-432-8635 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.

## American Foundation for Suicide Prevention

#### www.afsp.org

Mission: Save Lives and Bring Hope to Those Affected by Suicide. Established in 1987, the American Foundation for Suicide Prevention (AFSP) is a voluntary health organization that gives those affected by suicide a nationwide community empowered by research, education and advocacy to take action against this leading cause of death.

## National Suicide Prevention Lifeline https://suicidepreventionlifeline.org

The National Suicide Prevention Lifeline is a 24-hour, toll-free, confidential suicide prevention hotline available to anyone in suicidal crisis or emotional distress. Your call is routed to the nearest crisis center in the national network of more than 150 crisis centers. For assistance, call 1-800-273-TALK (8255), **TTY: 1-800-799-4889.** 

The Crisis Text Line www.crisistextline.org: Text HOME to 741741

Urban Trauma Center: 660 Winchester Avenue New Haven, CT 06511 203-776-8390 www.dncmhs.org Offering effective services for trauma and post traumatic stress.

## Employment

## Office of Disability Employment Policy www.dol.gov/odep

The Office of Disability Employment Policy (ODEP) is the only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities.

# Office of Personal Management, Federal Employment of People with Disabilities

#### www.opm.gov/disability

The Federal Government is actively recruiting and hiring persons with disabilities. We offer a variety of exciting jobs, competitive salaries, excellent benefits, and opportunities for career advancement.

## Rehabilitation Services Administration https://rsa.ed.gov

Our mission — to provide leadership and resources to assist state and other agencies in providing vocational rehabilitation (VR) and other services to individuals with disabilities to maximize their employment, independence and integration into the community and the competitive labor market.

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The Vocational Rehabilitation Program (formerly BRS)
Bureau of Rehabilitation Services - Department of Social Services
25 Sigourney Street-11th Floor Hartford, CT 06106
1-800-537-2549 (voice only)
(860) 424-4844 (voice); (860) 424-4839 (TDD/TTY)
1-800-537-2549; (860) 424-4844 http://www.brs.state.ct.us/
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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 for the VR program, an individual must have a physical or mental condition which poses a substantial barrier to employment, and must require VR services in order to prepare for, find and succeed in employment.

Ability Beyond Disability 4 Berkshire Blvd. Bethel, Connecticut 06801 1-888-832-8247 info@abilitybeyonddisability.org

Ability Beyond Disability's mission is to enable individuals whose independent living skills are impaired by disability, illness or injury, to 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.

# **Financial Assistance**

## 1-800-MEDICARE (1-800-633-4227) www.socialsecurity.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 that 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 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. To be eligible for a Social Security benefit, the worker must earn sufficient credits based on taxable work to be "insured" for Social Security purposes. Disability benefits are payable to blind or disabled workers, widow(er)s, or adults disabled since childhood, who are otherwise eligible. The amount of the monthly disability benefit is based on the Social Security earnings record of the insured worker. Supplemental Security Income (SSI) are payable to adults or children who are disabled or blind, have limited income and resources, meet the living arrangement requirements, and are otherwise eligible.

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.

## Husky Health of Connecticut, Charter Oak Health Plans, (formerly SAGA) 11 Fairfield Blvd. Suite 1, Wallingford, CT 06492 Telephone: 800-440-5071

This company manages all Title 19 or Medicaid products for all ages. The programs provide medical coverage assistance to low income persons.

Applications and approval is still done through the state DSS or Department of Social Services. All services included in the CT Medicaid program are covered, including homecare and skilled nursing facilities. Gaylord has a benefits Liason who can assist you with the application process. Your care manager can make a referral to Joan Hogan if that will be helpful to you.

Acquired Brain Injury (ABI) Waiver Department of Social Services 25 Sigourney St. Hartford, CT 06106-5033 1-800-842-1508 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 eligible for all Medicaid covered services. Application is made by contacting the Department's regional offices, and returning a completed ABI Waiver Request Form.

Personal Care Assistant (PCA) Waiver Department of Social Services 25 Sigourney St. Hartford, CT 06106-5033 1-800-842-1508 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 contacting the Department's regional offices, and returning a completed PCA Waiver Request Form.

'Money Follows the Person' Department of Social Services 25 Sigourney St. Hartford, CT 06106-5033 1-800-842-1508 www.ct.gov/dss 1-888 992 8637

'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 programs including Waiver programs and is currently a work in progress.

ConnPACE (Connecticut Pharmaceutical Assistance Contract to the Elderly and Disabled) Department of Social Services 25 Sigourney St. Hartford, CT 06106-5033 1-800-842-1508 www.ct.gov/dss

Only for people who have not worked enough quarters for Medicare plus a very low income. ConnPACE is a service that helps eligible senior citizens and people with disabilities afford the cost of most prescription medicines, insulin and insulin syringes and needles. If you are a Connecticut resident aged 65 or older, or with a disability aged 18 or older, you may qualify for ConnPACE. Eligibility is based on income. ConnMAP (Connecticut Medicare Assignment Program) Department of Social Services 25 Sigourney St. Hartford, CT 06106-5033 1-800-842-1508 www.ct.gov/dss

The Connecticut Medicare Assignment Program (ConnMAP) ensures that eligible Medicare enrollees are charged no more than the reasonable and necessary rate established by the federal government for Medicare covered services received from health care providers. Individuals who are residents of Connecticut, enrolled in Medicare Part B, and have incomes no greater than 165% of the income limits for the ConnPACE Program (currently \$41,415 if single or \$55,770 for couples) are eligible to participate in the program. ConnPACE program participants are automatically eligible for ConnMAP.

Alternate Care Unit - Connecticut Home Care Program for Elders (CHCPE) Department of Social Services 25 Sigourney St. Hartford, CT 06106-5033 1-800-445-5394 (toll-free) or 860-424-4904 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, 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 service 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 District**

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 Ave.Hamden, CT 06514203- 288-6282My Ride offers transportation for disabled 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

### **Milford Transit District**

203-874-4507 203-874-4507 ext 2 – 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.

## **Return to Driving Resources**

#### Easterseals Driver Assessment Program

158 State St Meriden, CT 06450 1(203)630-2208 or email driver@eswct.com

#### **McLean Outpatient Rehab**

75 Great Pond Road Simsbury, CT 06070 1(860)658-3745 Contact Susan Adamowicz, OTR/L, DRS

#### The Next Street Driver Rehab Services

76 Westbury Park Rd Suite 33E Watertown, CT 06795 1(860)483-7009 or email joan.cramer@thenextstreet.com http://rehab.thenextstreet.com

#### Norwalk Hospital Driver Rehabilitation Program

520 West Avenue Norwalk, CT 06850 Phone: 203-852-3400

## 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

#### **Chemical Use Education (CUE Group)**

The purpose of CUE group is to:

- Provide general education about substance use, and resources regarding the effects of substance use and behavior
- Help the patient make an informed decision regarding a healthy lifestyle
- Screen for patients who could benefit from treatment for chemical dependency

# Gaylord Specialty Healthcare's Family and Caregiver Support Group of Acquired Brain Injury Patients (BIFI):

The goals of this group are to:

- Provide family and caregivers with fundamental information about common symptoms and challenges after brain injury.
- Teach coping and problem solving strategies.
- Teach family members effective communication skills in order to develop a strong, mutually beneficial long-term support system.

Contact: Dorene Scolnic, LCSW (203)-679-3506

#### Brain Injury Coping Skills (BICS):

There is a need for care and support that includes both survivors and their families. As patients transition home both they and their support system often seek to learn additional coping skills to better cope with challenges. It is known that improved coping skills and increased social support leads to improved psychosocial outcomes.

This program offers eight weeks of structured support and assistance dealing with specific topics each week.

- The group is open to Gaylord patients, ideally 3-6 months post ABI (acquired, stroke, TBI, tumor)
- The patient needs to be able to participate in the sessions
- The family member or designated caregiver needs to attend the entire series alongside the patient

Contact: Dorene Scolnic, LCSW (203) 679-3506

## **Other Support Groups**

#### Aphasia Support Group

Where:	Cross of Christ Lutheran Church
	155 Hamilton Ave.
	Waterbury, CT 06706
When:	First Monday of every month from 6:30 p.m. to 8:00 p.m.
<b>Contact:</b>	blacheteaches@yahoo.com
	(203) 573-9303 (203) 592-6716

#### 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

## Accommodations

## **Guest Accommodations at Gaylord Hospital**

Our goal is to provide inviting and comfortable onsite housing while loved ones are at Gaylord by offering the Hoffman Guest Cottage, a two-bedroom guest house, and the MoraLee Guest Cottage with four individual suites. For a nominal fee, family members can be steps away from the hospital, with access to our beautiful grounds, cafeteria, and other resources, as you support your loved one and participate in his or her recovery. If you are interested in booking accommodations please contact the Patient Relations Department at (203) 741-3328. Accommodations are based on availability.



MoraLee Guest Cottages



The Maximilian E. and Marion O. Hoffman Cottage

Some area motels and inns have made special rates available to those planning on extended stays while visiting Gaylord patients or receiving treatment. Please mention Gaylord when making reservations. Discount programs and hotel names may change at the discretion of the hotel management.

# Wallingford

Courtyard by Marriott 600 Northrop Road Wallingford, CT 06492 (203) 284-9400

Fairfield Inn 100 Miles Drive Wallingford, CT 06492 (203) 284-0001

# Meriden

Hawthorn Suites 1151 East Main Street Meriden, CT 06450 (203) 379-5048

Red Roof Inn 10 Bee Street Meriden, CT 06450 (203) 235-5154

Four Points by Sheraton 275 Research Parkway Meriden, CT 06450 (203) 238-2380

# North Haven

Best Western Plus 201 Washington Avenue North Haven, CT 06473 (203) 239-6700 This educational resource was assembled through the dedication of our excellent clinical team. It started as an idea and bloomed because of our dedicated staff.



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:

Dr. Glen Johnson Clinical Neuropsychologist Clinical Director of the Neuro-Recovery Head Injury Program 5123 North Royal Drive Traverse City, MI 49684 (231) 935-0388 debglen@yahoo.com www.tbiguide.com

