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REHABILITATION

Road to Recovery

The Essential Brain Injury Guide

Version III

A partnership of Michigan State University and Peckham, Inc.

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Version 3

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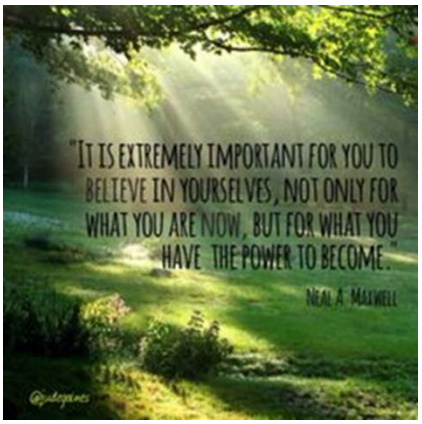


Brain injury is often called an "invisible" disorder or disability. It is termed this because the impairments and effects of the injury are not always visible or immediately evident. However, to anyone that has suffered a brain injury, or to those that care about someone who has, the effects of a brain injury are complex and can pervade many aspects of the individual's life. As such, brain injury can be difficult to understand, the symptoms can be scary, and the rehab process can be challenging. Those going through the journey of recovery following a brain injury may feel insecure about their future and wonder if there is hope for healing. Those injured and their loved ones may feel isolated and cut off from the world. It is the intent of this guide to provide education about brain injury and what one may expect from the rehab process. The purpose of this guide is also to convince those that are injured, and their loved ones, that there is reason to be optimistic and hopeful about recovery and a healthy and happy life post brain injury.

The reader will be accompanied through this guide by Jeff and Glyni. Jeff will be sharing his perspective as a brain injury survivor, while Glyni will be sharing her perspective as the wife of a brain injury survivor. Their stories will help articulate the personal side of the recovery story—how their lives were shattered by brain injury and the process that they experienced to put the pieces back together.

There are many medical and rehabilitation terms throughout this guide. To help, bolded words through the guide will have corresponding definitions located in the glossary section. However, it is understood that not all questions will be answered with the contents of this guide. Every individual is unique; likewise, every brain injury is unique. Therefore, it would be natural to have specific questions as the reader progresses through the information in this guide. The reader is encouraged to utilize the Notes section of this guide to record questions about the individual circumstances that may be presenting themselves and bring the questions to a medical professional, rehabilitation team, or appropriate support system.

The reader will also notice some inspirational quotes throughout the guide—the road to recovery can be very challenging; encouragement is often needed!

The information in this guide has been provided by the experts at Origami Rehabilitation. Origami is a leader in public education and awareness surrounding brain injury issues. Origami is also a state-of-the-art innovative, comprehensive rehabilitation program with a holistic philosophy that treats individuals and families as unique persons with unique needs. For more information, visit www.origamirehab.org.

Etiology and Epidemiology

Defining Brain Injury

Just as there are no two individuals exactly alike, no two brain injuries are the same. A brain injury can come from a variety of sources and have varying effects on the individual, which will be discussed later in this guide. First, though, it is important to know the cause and prevalence of brain injury.

"After I graduated from high school, I was in a car wreck when a drunk driver ran a stop sign. I suffered a closed head injury with shearing that left scar tissue on my brain. I awoke from a coma in the hospital, tied to the bed with a feeding tube down my throat. My head was shaved and tubes and wires were everywhere. My grandparents told me that our family had been in a car wreck. My dad was still in a coma. My sister had multiple cut nerves and broken bones. My mom and brother had been killed." - Jeff

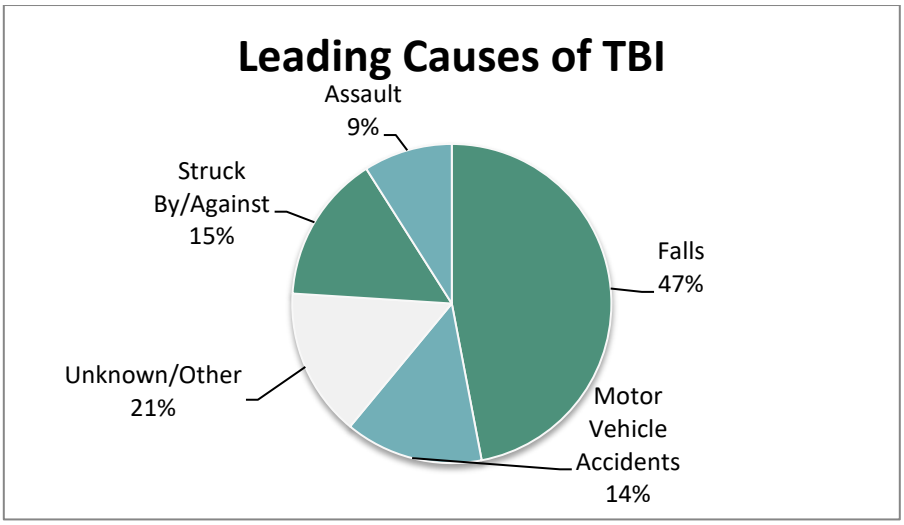
An **acquired brain injury** is an injury to the brain that has occurred after birth; these injuries are not a result of heredity, nor are they congenital or degenerative. Examples include:

- Traumatic brain injury
- Stroke
- Infections (encephalitis, meningitis)
- Seizures
- Tumors
- Lack of oxygen to the brain (anoxia, hypoxia)
- Neurotoxic poisoning (ingestion of insecticides, solvents, lead)

A **traumatic brain injury (TBI)** is an injury to the brain caused by an outside force which is sudden and traumatic in nature. Causes include:

- Hitting a stationary object (such as a windshield or steering wheel)
- Being struck by an object or a "blow to the head" (such as from an assault, flying object, or violent collision in sports)
- Penetration (such as from a bullet wound)
- Falls
- Violent shaking (such as whiplash or shaken baby syndrome)
- Exposure to an explosion (such as a blast from an Improvised Explosive Device – IED)

Figure 1: Leading causes of traumatic brain injury (TBI) according to Centers for Disease Control



Data comes from CRS Report for Congress 2013: http://www.fas.org/sgp/crs/natsec/RS22452.pdf

Brain Injury Prevalence and Risk

It is important for those living with brain injury, as well as those that care for and love them, to know that they are not alone! As the statistics below demonstrate, brain injury is a highly prevalent disorder that affects individuals and families of all walks of life throughout every community. The following statistics are from the Centers for Disease Control and the Brain Injury Association of America:

- 5.3 million Americans, about 2% of the U.S. population, currently have a long term or lifelong need for help to perform activities of daily living as a result of a TBI
- 2.8 million people sustain a TBI each year in the United States. Of those people:
  - 64 ,000 die
  - 282,000 are hospitalized
  - 2.5 million (nearly 90%) are treated and released from an emergency department
- 917,000 people suffer an acquired brain injury (non-TBI) each year. The causes of which are:
  - Stroke (795,000)
  - Tumor (64,530)
  - Aneurysm (27,000)
  - Viral Encephalitis (20,000)
  - Multiple Sclerosis (10,400)
  - Anoxic/Hypoxic (no national data available)
- More than 430,000 military service members have sustained a TBI between January 2000 and January 2020
- After the first TBI, the risk for a second brain injury is 3 times greater
- After a second TBI, the risk is 8 times greater
- Children aged 0 to 4 years, older adolescents aged 15 to 19 years, and adults aged 65 years and older have the highest prevalence
- In every age group, TBI rates are higher for males than for females

Brain Injury Severity

The effects of brain injury are complex and vary greatly from person to person. The information within this section consists of common indicators of the differing severity levels of brain injury. The lines between mild, moderate, and severe are often blurry and one might hear that their loved one has sustained a "mild-moderate" TBI.

"When I got to the hospital, I was told that they didn't know if Bill would make it, his brain injuries were so severe. They let me see him before they wheeled him into the operating room. They had anesthetized him already, but I hoped he could hear me. I yelled at him: 'You can't leave me! I'm too young to be a widow and I refuse to be! I need you and I love you so much! Don't you dare leave me!' I understood that Bill's injuries were very severe; it seemed like there was very little of his brain that wasn't injured. I knew I'd never have the husband I used to have." - Glyni

The signs and symptoms listed in this section identify common language and practice surrounding the classification of brain injury severity. It is important to understand that often severity level is discussed in terms of the initial injury and recovery is possible at all levels!

Mild TBI or Concussion

- Loss of consciousness (LOC) may be very brief, usually a few seconds or minutes or may not occur at all. The person may be dazed or confused.
- Testing and scans of the brain may appear normal
- Most common: 75%-85% of all brain injuries are mild
- 90% of individuals recover within 6-8 weeks, often within hours or days, but 10% experience deficits, which may not be evident immediately
- Multiple concussions or mild brain injuries over time (e.g., sports injuries or domestic violence) increases the severity of deficits
- Signs and symptoms of a mild brain injury or concussion may include:
    - Brief period of unconsciousness
    - Confusion
    - Dizziness
    - Headache
    - Sensory problems, such as blurred vision, ringing in the ears or a bad taste in the mouth
    - Memory or concentration problems
    - Mood changes
- Concussion symptoms will vary with the individual
    - Not every individual will have the same number of symptoms, the same kind of symptoms, or the same effects of these symptoms

Moderate TBI

- Loss of consciousness lasts from a few minutes to a few hours
- Confusion lasts from days to weeks
- Physical, cognitive, and/or behavioral impairments last for months or are permanent

- EEG/CAT/MRI are positive for brain injury
- If the injury is moderate to severe, the list of signs and symptoms grow to include:
  - Persistent headache
  - Repeated vomiting or nausea
  - Convulsions or seizures
  - Inability to awaken from sleep
  - Dilation of one or both pupils of the eyes
  - Slurred speech
  - Weakness or numbness in the extremities
  - Loss of coordination
  - Increased confusion or agitation

Severe TBI

An individual who suffers a severe TBI will endure a prolonged unconscious state or coma that lasts days, weeks, or months.

Measuring Severity

There are two common measurements that are utilized to measure initial brain injury severity. Those injured, and their support systems, could hear numeric scores on the Glasgow Coma Scale and/or the Rancho Los Amigos Cognitive Scale. Initial assessments and evaluations of the person injured will result in scores that determines severity level and potential courses of action.

Table 1:
Glasgow Coma Scale

Eyes Open	**Score**
Spontaneously	4
To Verbal Command	3
To Pain	2
No Response	1
Best Motor Response	**Score**
Obeys to verbal command	6
Localizes Pain	5
Flexion- Withdrawal	4
Flexion- Abnormal	3
Extension	2
No Response	1
Best Verbal Response	**Score**
Oriented and Converses	5
Disoriented and Converses	4
Inappropriate Words	3
Incomprehensible Sounds	2
No Response	1
GCS Total	**3-15**

Glasgow Coma Scale (GCS)

Upon evaluation, scores are given in three areas: Eyes Open, Best Motor Response, and Best Verbal Response. These three scores are added up to get the total GCS score with a possible range of 3-15. The lower the total GCS score indicates a higher level of brain injury severity.

Rancho Los Amigos Cognitive Scale

The Rancho Los Amigos Cognitive Scale is defined by eight levels that are based on observations determining a person's cognitive state that range from coma to appropriate behaviors and cognitive responses. As individuals progress through healing and/or rehabilitation, they may move from one level to the next. However, depending on the severity and nature of the injury, an individual may remain at any given level for an extended period, which may be difficult to predict.

Table 2: Rancho Los Amigos Cognitive Scale

	Responses from the Individual
Level 1	No response to pain, touch, sound, or sight
Level 2	Generalized reflex to pain response
Level 3	Localized Response. Patient begins to move their eyes and look at specific people and objects. May turn toward or away from loud noises. May follow simple command, such as "squeeze my hand". Responses are inconsistent.
Level 4	Confused/Agitated Response. Patient is very confused and agitated about where he/she is and what is happening in the surroundings. May be restless, aggressive, or abusive (verbally and/or physically). Safety and deficit awareness are important issues/concerns. **Do not interpret the agitation and confusion as regression, but rather as progress. The patient will have little recall to this period of time.
Level 5	Confused, Inappropriate, Non-agitated Response. Patient is confused and does not make sense in conversations but may be able to follow simple directions. Stressful situations may provoke upset, but agitation is no longer a major problem. Frustration may be experienced as elements of memory return. Easily distracted by environment and gets overstimulated.
Level 6	Confused, Appropriate Response. Patient's speech makes sense and can do simple things like dressing, eating, and teeth brushing. May need help getting started and stopping tasks. Learning new things is difficult, attention increases to around 30 minutes.
Level 7	Automatic, Appropriate Response. Patient behaves appropriately in familiar settings, performs daily routines automatically, and shows carry-over for new learning at lower than normal rates. Patient initiates social interactions, but judgment and safety remain impaired.
Level 8	Purposeful, Appropriate Response. Patient oriented and responds to the environment but abstract reasoning abilities are decreased. Acknowledges impairments but has difficulty self-monitoring. Emotional issues (depression, irritability, etc.) may occur.

Neuroanatomy

> "I was afraid to look up anything about TBI on the internet for fear of what I'd find. I knew that a 'mid-line shift' was really bad—one of my girlfriends looked it up for me, and told me that because of that injury, my husband might be blind when he awoke from his coma. He dodged that bullet. I was hardly functioning. I found it very hard to take in information. I made two of his colleagues, who were also Physician Assistants, my 'go-to peeps.' They would translate what the doctors told me, tell me what questions to ask, and what information to get. I had a group of girlfriends who took turns coming up north to stay with me; they didn't want me to be alone for any length of time, because I wasn't eating much and was practically living in the ICU." - Glyni

The human brain is organized into different parts based upon the function it generally controls. These areas communicate and work together to carry out tasks. Understanding which area of the brain was injured helps one to better understand some of the changes or challenges he or she may experience. Figure 2 identifies the different parts of the brain and the corresponding functional controls.

Figure 2: Brain and Behavior Relationships

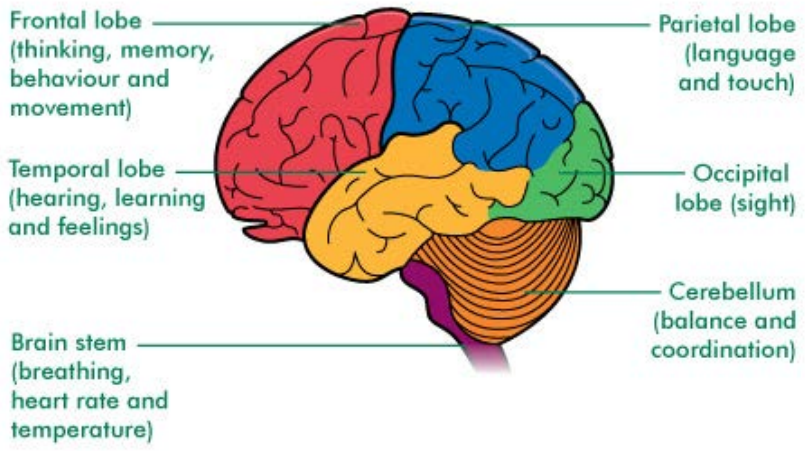


Image comes from: http://fashion-kid.net/parts-of-the-brain-lobes-and-their-functions.html

The essential functions the brain plays in coordinating the body's automatic or reflexive activities can be easily forgotten. These activities, such as breathing, seeing, maintaining balance, tasting, and swallowing can be taken for granted; however, there is the possibility of mild to severe disruption of these functions with an injury to the brain stem. Within the brain stem are twelve cranial nerves that control these activities. Table 3 identifies these nerves and their functions.

Table 3: Cranial Nerves and Function

Cranial Nerve		Function
I.	Olfactory	Smell
II.	Optic	Sight
III.	Oculomotor	Eye movement; Pupil dilation
IV.	Trochlear	Eye movement
V.	Trigeminal	Sensation in face, teeth, eyes and lower jaw; muscles for chewing
VI.	Abducens	Eye movement
VII.	Facial	Taste; Facial expression; Tear and saliva
VIII.	Vestibulocochlear	Hearing; Balance
IX.	Glossopharyneal	Taste; Tongue and throat movement; Swallowing; Gag reflex
X.	Vagus	Swallowing; Breathing; Heart rate; Stomach acid
XI.	Spinal Accessory	Head, neck and shoulder movement
XII.	Hypoglossal	Tongue movement

The brain is divided into two hemispheres, the right and the left. The right side of the brain controls more nonverbal functions, such as visual-spatial skills, reading maps, and expressing / understanding emotions. The left side of the brain in most people controls verbal functions, such as language, thinking, and memory involving words. It also controls movement and sensation on the right side of the body. So, if a person is injured on the left side of the brain, you may see weakness or inability to move the right side of their body.

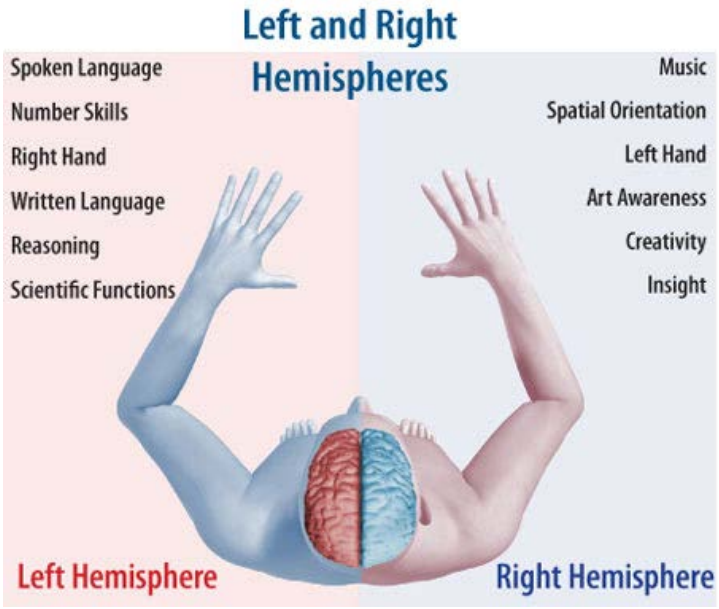
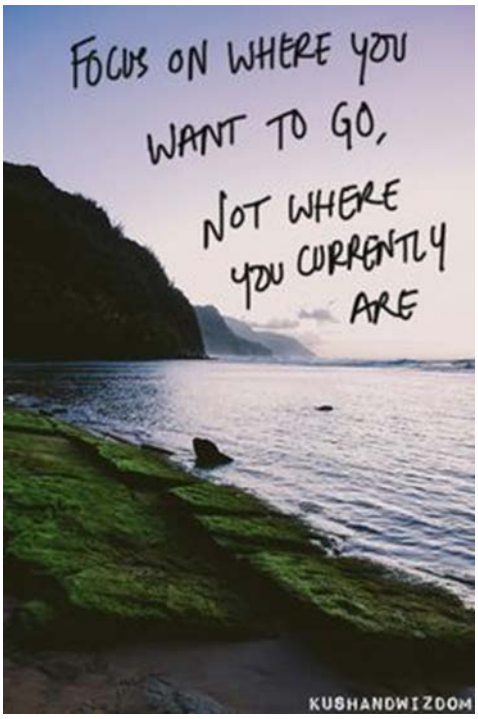


Image comes from http://www.msha.com/services/ortho_neuro/stroke_center/stroke_education.aspx

Injury to the brain may result in swelling or bleeding within the tissue of the brain. This can lead to a cascade of chemical events that can cause brain damage. The brain may shift, or pressure may increase which can deprive parts of the brain of much needed oxygen to keep the brain healthy and functioning. However, bleeding or swelling does not need to be present for changes to occur.

The brain is composed of **neurons** and **neurotransmitters** (chemicals) which keep the brain functioning quickly and automatically. During a concussion injury, or mild TBI (mTBI), a sudden movement can cause the brain to shift around or twist in the skull, stretching and damaging the brain cells and producing chemical changes in the brain. Even though these types of injuries are often not life threatening, their effects can be serious, particularly when multiple concussions occur over a period of time. This type of injury is not easily detected by imaging or brain scans, therefore medical professionals rely on the signs or symptoms of the injury to diagnose mTBI.



It is important to seek medical attention and track observed changes, even if you have been told "it's just a concussion". Rehabilitation services can help to restore lost function or prevent further decline from concussions and mTBI.

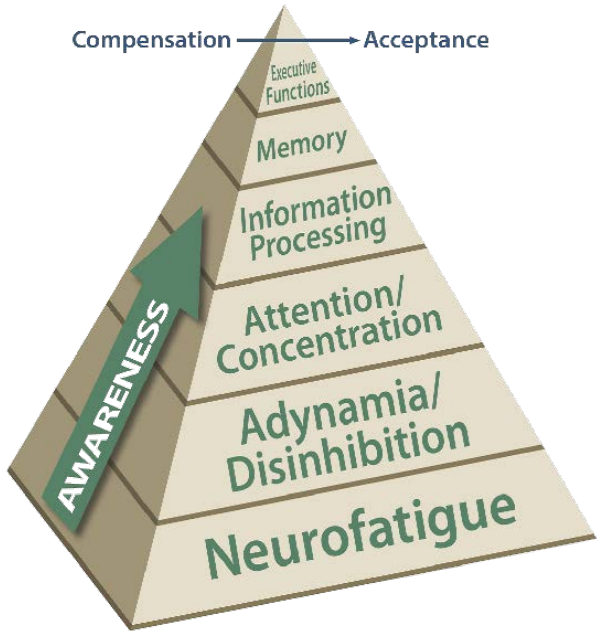
Possible Challenges after Brain Injury

Cognitive Challenges

Some of the changes related to brain injury may be internal and not visible to others. The person may walk and talk the same but feel very different due to changes in thinking. Cognitive skills refer to thinking abilities or mental processes – it refers to how the brain takes in information and decides what to do with it. These changes may only be noticed by the survivor, or close family and friends; however, they can impact how a person performs daily tasks.

Furthermore, a person can become disoriented or confused with regards to times and place. **Confabulation** can happen to fill in memory gaps.

"I am most aware of problems with memory. I use strategies like a smartphone, notebook, calendars and lists. But, I still trust others for recall. I struggle with Adynamia. It takes a conscious effort to motivate myself to do things; even basic daily routines. Neurofatigue makes my brain lose optimum functioning ability because my brain has to work twice as hard to do half as much. When my brain gets tired, I get tired. I have more difficulty paying attention, processing information and making decisions. I have found that when I take a nap every 4 hours, I wake refreshed and able to proceed with my day. Social interactions and new experiences with lots of people cause me anxiety. I also have to concentrate on information and facial expressions because I don't want my interactions to be flat. I plan a nap before activities so that my brain is refreshed." - Jeff



Dr. Yehuda Ben-Yishay, with the Rusk Institute of Rehabilitation Medicine, at New York University, has developed the Hierarchy of Cognitive Functions. The Hierarchy of Cognitive Functions is a useful tool in establishing a common language for those on a person's treatment team (therapists, physicians, family, etc.) as well as to better understand the cognitive problems he or she may be experiencing. The model works from the bottom up so that each level of functioning is dependent upon how well the lower levels are working. For example, if a person is experiencing neurofatigue (mental fatigue), the model helps to explain why he or she may be more impulsive (disinhibition) or may have difficulty keeping up in a conversation (slowed information processing). The hierarchy helps everyone on the team to better understand where the problem lies (level of hierarchy), what these problems may look like (signs and symptoms), and the strategies that can be used to manage it.

Neurofatigue

Definition	Fatigue that is organically based and not due to excessive activity or abnormal sleep patterns. It can emerge suddenly without warning, especially after engaging in a cognitively demanding task.
Signs and Symptoms of Problems	Lack of Energy to Engage: Difficulty engaging in activities of daily living, communicating with others, or social activities. Low Arousal: Difficulty waking up and staying awake throughout the day. It may require noise and/or touch (auditory and tactile cueing) to wake from sleep. It may be hard to open the eyes. Decreased Alertness: Decreased ability to maintain mental awareness of surroundings, leading to decreased response to them.
Strategies for Survivors and Significant Others	• Build awareness of the causes and effects of neurofatigue. • Identify early signs of fatigue (yawning, slow motion, in a "fog," etc.). • Trust others when offering feedback about your apparent fatigue levels. • Establish a routine for activities, bedtime, and wake times. • Break large tasks into manageable chunks-use a checklist. • Minimize stimulation in environment when completing tasks.

(Neurofatigue, Continued)	• Manage the "flood" of input. • Consult physician to inquire about side effects of medications as they could possibly induce drowsiness and be prescribed for later in the day. • Adjust diet, water intake, and exercise to facilitate a healthy lifestyle and to promote healing.

Adynamia

Definition	Low mental energy or apparent lack of will. Not "dynamic".
Signs and Symptoms of Problems	Trouble Initiating: Hard to get started on things (misperceived as being lazy). Difficulty Generating Thoughts/Ideas: Run out of ideas quickly. Does not give a lot of details in communication. Lack of Spontaneity: Loss of "spirit." Others think you are not interested or are just "going through the motions." Face often does not show emotion. "Poker Faced."
Strategies for Survivors and Significant Others	• Use a routine to encourage increased task anticipation. • Break large tasks into manageable chunks. • Schedule tasks and stick to the scheduled due date. Prepare by using notes to help initiate conversation. • Use to-do lists, checklists, timers, watches, alarms, and other adaptive devices to improve ability to self-initiate tasks. • Allow others to help cue you to get started or suggest where to begin. • Establish "accountability contracts" with supportive others to help initiate activities. • Become aware of facial expressions, posture, and eye contact (i.e., video tape self). • Exaggerate emotions and speak louder (reduces monotone). • Do not tell the person that they are "lazy"-understand they most likely know what needs to be done but are having a difficult time getting started. Offer support to get started/initiate tasks. • Provide written checklists to encourage participation. • Cue as needed to begin tasks, verbally or with timers/alarms.

Disinhibition

Definition

A syndrome marked by difficulty properly directing and controlling energy and emotions.

Signs and Symptoms of Problems

Impulsivity: Doing or saying things without considering the consequences. Making decisions before thinking about all of the information.

Feelings or behaviors come on too strong and/or too fast: Feelings come to the surface and are hard to hold back. Reacting to small things with too much emotion.

Irritable and Easily Frustrated: Hard to forget even small irritations. Brooding. Often require others to help calm down.

Restlessness: Hard to keep still. Intense and frequent need to move or fidget.

Emotional Flooding: Can become easily overwhelmed when feeling challenged socially or cognitively. Mind "goes blank." Once flooded, it is temporarily impossible to think clearly or act purposefully.

Strategies for Survivors and Significant Others

- Visually/verbally cue the person to slow down.
- Build in delays. Establish automatic "pauses" between each task. Use a stopwatch if needed.
- Ask the individual if they would do better if they put more thought into a decision.
- Consult a coach or family member before acting and gather further feedback.
- Use this sequence "Stop, Think, Act, and Evaluate" and analyze how they did afterward.
- Use self-talk strategies (i.e., could I go slower? Did I think about this long enough?).
- Be direct in response to inappropriate behaviors (i.e., interruptions, inappropriate remarks, tone of voice, awkward facial expressions).
- In a tactful way, let the person know how they are coming across (i.e., "when you say I do this, it makes me feel…").
- Ask permission to videotape an interaction with the person and later analyze with the person.
- Encourage use of breaks to relax, calm down, and re-attempt communication when ready.

(Disinhibition, Continued)	• Verify what was really seen, heard, or felt to know if feelings are justified. • Seek coaching • Teach relaxation strategies. • Ask the other person to slow down if they are making you irritated. • Excuse self from current situation if too upset.

Attention/Concentration

Definition	Staying awake, alert, and ready while focusing and keeping a train of thought. There are different levels of attention/concentration: Sustained, selective, alternating, and divided. • Sustained Attention: staying focused on a single task for a period of time. • Selective Attention: filtering out distractions and focusing on desired stimuli. • Alternating Attention: switching from one task to another and then back again. • Divided Attention: attending to more than one stimulus at a time.
Signs and Symptoms of Problems	Hard to Stay Alert: Not enough mental energy to engage fully in the environment. Hard to Focus Attention: Easily distracted by noises and things around you. Distracted by personal thoughts, feelings, and worries. Lose "Train of Thought:" Once able to focus, a person may lose "train of thought" or concentration if distracted. It may be hard for a person to make a point without getting off track and "rambling."
Strategies for Survivors and Significant Others	• Reduce environmental distractions (i.e., close doors, reduce glare) and allow extra time. • Use cues and alarms as needed to sustain or reset focus. • Allow others to redirect you back to the current topic when conversation becomes unfocused. • Focus on giving eye contact during conversation, ask questions, and use nonverbal communication.

(Attention/Concentration Continued)	• Use a line guide to reduce amount of information to attend to on a page. • Scan items left to right and top to bottom while using finger to anchor eyes. • Repeated visual/verbal cues to "slow down" and "pay attention to details" and "double/triple check your work".

Information Processing

Definition	Taking environmental stimulation in through the five senses, interpreting it, and responding.
Signs and Symptoms of Problems	Thinking Speed and Response Times are Slower: It takes longer to understand sensory information and make sense of what is going on in a situation. There may be a long pause before the person responds with words or behavior. Processes only Fragments of Information: Because of the slowed processing speed, parts of information heard or seen may be missed. Social Inappropriateness: Difficulty interpreting and making sense of social cues and body language of others.
Strategies for Survivors and Significant Others ***(Information Processing)***	• Encourage organization of information given. • Verify written, read, and verbal information gathered. • Encourage single task completion; rather than focusing on multiple tasks. • Concentrate on accuracy first and speed later. • Write information down to give to the individual to allow extra time for better comprehension/understanding. • Ask others to slow down or repeat information. • Reduce visual distraction, auditory distraction, and internal distractions. • Practice, Practice, Practice to improve efficiency of specific skill areas. • Improve word retrieval and thought organization through practice conversations.

Memory

Definition

Taking in new information, holding on to information, and recalling information when needed.

Types of Memory, processed by different areas of your brain:

- Short term: holding information for a short period of time (minutes).
- Long term: library and record center of stored information.
- Episodic: recalling personal events (i.e., errands, appointments).
- Procedural: remembering the steps of a task (i.e., laundry, driving a car).

Signs and Symptoms of Problems

Difficulty Retaining New Information: Hard to hold on to even brief instructions or explanations. Difficulty remembering what was said at the beginning of a conversation.

Difficulty Storing New Information: Information is not retained long enough to be permanently stored.

Difficulty Retrieving Stored Information: Hard to recall the main point of a conversation, even if it just occurred.

May forget important things learned from experience, causing mistakes to be repeated.

Strategies for Survivors and Significant Others

- Use external strategies (i.e., calendars, lists, planner, timers).
- Increase awareness of problems to increase use of strategies.
- Follow a daily structure/routine.
- Allow repetition of new information or tasks to assist learning and recall.
- Provide information in small pieces rather than lengthy ones.
- Provide visual as well as verbal instruction of new tasks.
- Help to develop associations/reminders to improve carryover of information learned (associate old information with new).
- Determine strengths and weaknesses with memory, and use strengths as much as possible (i.e., verbal memory versus visual memory versus learning by doing).
- Write important information down in a consistent location and organized fashion.
- Place items in a common location (i.e., keys in bowl by front door, bills in tray).
- May need to rely on trusted others for memory.
- Journal the day's events as they occur.

Executive Functions

Definition

The ability to reason, plan, problem solve, make inferences, and/or evaluate results of actions and decisions.

Signs and Symptoms of Problems

Poor Convergent Reasoning: Hard to narrow down the key point or main idea of something. Hard to choose the best possible solution to a problem.

Poor Divergent Reasoning: Hard to come up with more than one way of thinking about something. Hard to see another point of view. Difficulty with empathy. Hard to think of multiple solutions to a problem, causing one to get stuck if one solution does not work.

Difficulty with Goal-Oriented Behavior: Hard to set reasonable, attainable goals. Difficulty thinking of all the steps required to reach a goal. Difficulty prioritizing what to do first. Problems evaluating how your plan is going, fixing mistakes, and changing the plan as needed.

Making Poor Decisions: Acting on false or incomplete information.

Strategies for Survivors and Significant Others

- Encourage use of all strategies required in hierarchy to this point.
- Cue as needed to provide multiple alternatives to problems.
- Avoid abstract language, be concrete and to the point.
- Do not confuse stubbornness with decreased flexibility. A person may be unable to see your point of view.
- Write things down to increase concreteness.
- Making pro/con lists to help with decision making.
- Identify the relevant details and help to lead the person to a reasonable solution.
- Answer who, what, where, why, and how questions before deciding to ensure all the essential information has been gathered first.
- Break directions down into sequential parts.
- Provide set-up for tasks to assist participation.
- Use written checklists for task steps.
- Encourage the use of a planner.
- Assist with set-up of filing system, notebook, etc.
- Be consistent and establish structure.
- Pre-plan activities to consider all aspects including amount of time, items needed, sequence of events, etc.

(Executive Functions, Continued)	• Take the time needed to think of all the possible solutions to the problem at hand. • Verify that you are not missing a step in a sequence by stopping frequently and reviewing what has been done and what still needs to be completed.

Physical Challenges

Those unfamiliar with brain injury may assume that the only areas affected are those associated with thinking. However, those that have sustained an injury, and those that care for them, know all too well that physical changes are often present. These challenges can manifest through changes in ease of movement, pain, sensory and perception changes, and sleep difficulties. This section will provide an overview of possible physical difficulties that may be associated with a brain injury. Each area will have some examples and possible strategies that may be suggested throughout the rehabilitation process.

Motor Difficulties

Examples	Potential Strategies
paralysis, poor balance, lowered endurance, inability to coordinate movements (**ataxia)**, **abnormal tone**, muscle stiffness	Physical Therapy may be indicated and can include: • balance retraining • strength and endurance exercises • neuromuscular re-education • stretching • education in home exercise programs

Sensory Changes (non-vision related)

Examples	Potential Strategies
sensitivity to noise, hearing loss, loss of taste and smell, decreased sensation, numbness / tingling, pain and headaches	• wearing ear plugs or hearing aids for hearing issues • if food intake is a problem due to impaired taste causing decreased appetite, then a food log may be helpful to track intake and ensure proper nutrients and calories are being consumed • utilizing spices to increase flavors of food • asking for assistance when testing temperatures of water or hot surfaces to ensure safety if decreased sensation is an issue

Oral and Speech Movement

Examples	Potential Strategies
slowed or slurred speech, difficulty chewing and swallowing (**dysphasia**), choking, difficulty forming words (**dysarthria)**, difficult with verbal communication (**aphasia)**	• exaggerating movements of the lips and tongue • break speech into phrases, increase breath support • alter speech rate • exercises to improve the range of motion and coordination of oral structures • exercises to improve the parts used for speech (i.e., lips, cheeks, tongue) • altering texture and consistency of food or liquid • strategies to improve the safety of swallowing

Vision and Perceptual Changes

Examples	Potential Strategies
light sensitivity, visual-perceptual difficulties, visual field cuts, **apraxia**, difficulty with spatial relations, **oculomotor** dysfunction, focusing difficulties, strain while reading or inability to track, traumatic strabismus (may cause head tilts), **diplopia, nystagmus**	• wearing sunglasses to dim the light and/or turning lights down for light sensitivity • vision therapy as indicated by a Neuro-Visual Optometrist • glasses that may include prisms or specialized lenses for visual field issues • intermittent eye patching

Regulatory Functions

Examples	Potential Strategies
fatigue, difficulty regulating body temperature, difficulty regulating consumption of food and liquids, loss of bowel and bladder control	• taking frequent naps or rest breaks where stimulation can be decreased to manage fatigue • dress in layers so clothes can be added or removed based on your setting • tracking sheets to track food, liquids, and/or bowel and bladder

Sleep Difficulties

Examples	Potential Strategies
drowsiness, sleeping less than usual, sleeping more than usual, trouble falling asleep	• utilizing relaxation strategies before sleep • establish and maintain a healthy bedtime routine • take naps/rest breaks throughout the day • establish a schedule for your day

Vestibular Disorders

Examples	Potential Strategies
dizziness, disequilibrium, vertigo, balance difficulties	• targeted physical therapy evaluation and treatment

Behavioral and Emotional Challenges

A person experiencing brain injury may have a range of emotional problems including difficulties controlling mood, anxiety, and depression, as well as outbursts of uncontrolled crying and/or anger. These challenges could have a powerful impact on the day-to-day functioning of the individual with the injury.

"Honestly, I feel robbed, and if I let myself dwell on all of it, I get very angry at the injustice of it all. I live alone now and have for the past 2 ½ years. Bill and I are now apart, not just physically; but emotionally, because of his adynamia, mentally because of his injured brain, and psychologically because I've had to learn how to distance myself sometimes – so I don't get hurt. Much easier said than done. We are 'together alone.' He and I have gone from never running out of things to talk about, to struggling to communicate with each other. Talking on the phone is very hard. I constantly search for things to tell him, but he doesn't seem interested or care about any of it. I love this man so much, but ironically, the staff that work with him spend more time with him than I do, which hurts." - Glyni

Behavioral and emotional changes may profoundly impact the lives of those that have a meaningful relationship with the person that suffered the injury. It is important for both the person with the injury and his/her loved ones to understand that the changes in behavior and emotional connectivity are a result of the injury and the challenge to overcome these changes can be daunting and taxing on a relationship. It is understandable, and may be recommended, for loved ones of a person with brain injury to seek out assistance with the challenges that have manifested in their relationship since the injury. This section gives an overview of possible behavioral and emotional challenges that may be present after brain injury, as well as possible strategies that may be suggested during rehabilitation.

Difficulty Controlling Emotions or Mood Swings

Some people may experience emotions very quickly and intensely but with very little lasting effect. For example, they may get angry easily but get over it quickly. Or they may seem to be "on an emotional roller coaster" in which they are happy one moment, sad the next and then angry. This is called **emotional lability**. Some individuals may experience emotional flooding, becoming overwhelmed by emotions.

Strategies:

- Learn to identify and express emotions constructively.
- Increase self-monitoring of responses and learn healthy coping strategies to manage feelings of anger.
- Learn healthy coping strategies, including relaxation, cognitive challenging / reassuring thinking, behavioral activation, and communication strategies. Strategies to be applied individually and with support to improve interactions with others.

Temper Outbursts and Irritability

Family members of individuals with brain injury often describe the injured person as having a "short fuse", "flying off the handle" easily, being irritable, or having a quick temper. Studies show that up to 71% of people with brain injury are frequently irritable. The injured person may yell, use bad language, throw objects, slam fists into things, or slam doors.

Strategies:

- Encourage use of breaks to relax, calm down, and re-attempt communication when ready.
- Seek coaching.
- Ask the other person to slow down if they are making you irritated.
- Excuse self from current situation if too upset.
- "SAVE" strategy (Stop, Ask, Verify, Evaluate).

Depression

Feelings of sadness, frustration, and loss are common after brain injury. These feelings often appear during the later stages of recovery, after the individual has become more aware of the long-term situation. If these feelings become overwhelming or interfere with recovery, the person may be suffering from depression. Symptoms of depression include feeling sad or worthless, changes in sleep or appetite, difficulty concentrating, withdrawing from others, loss of interest or pleasure in life, lethargy (feeling tired and sluggish), or thoughts of death or suicide.

Strategies:

- Learn and apply cognitive-behavioral techniques that examine depressive thoughts and feelings, substituting them with positive and functional ones.
- Use behavioral activation strategies, such as being involved in pleasurable activities and becoming more social active, to improve mood and quality of life.

Anxiety

There are several forms of anxiety. People with brain injuries may feel anxious without exactly knowing why. Or, they may worry and become anxious about making too many mistakes, or "failing" at a task, or if they feel they are being criticized. Many situations can be harder to handle after brain injury and cause anxiety, such as being in crowds, being rushed or adjusting to sudden changes in plan. The anxiety may also come on a suddenly and be intense (heart is racing, feel like you are going to die, can't breathe); you are likely having a panic attack. Some individuals with brain injury experience Post-Traumatic Stress Disorder (PTSD), replaying in their minds elements of the traumatic event over and over again, causing them great distress and reducing their functioning.

Strategies:

- Explore anxiety and PTSD symptoms while processing experiences, engaging to address thoughts, and using coping strategies while limiting avoidance and building tolerance of specific triggers.
- Use deep breathing techniques to reduce stress and anxiety.
- Utilize relaxation methods to reduce stress and anxiety.

There are six common challenges that must be addressed during brain injury rehabilitation. Each of these challenges represents a continuum, ranging from the more basic neuropsychologic-cognitive to the more psychologic.

Engagement

Engagement is referred to as the need to become optimally activated and to improve basic and higher-level disturbances in attention and concentration. Engagement is also defined as the need to become personally motivated to engage in a purposeful and deliberate manner on remedial tasks. It is important for clients to view such remedial tasks as relevant to their ultimate rehabilitation goals.

Awareness

This is one of the most prevalent problems in rehabilitation for individuals with brain injuries. Lack of deficit awareness can result in unrealistic expectations of their rehabilitation goals. The lack of awareness and realism is a direct result in the client's cognitive deficits from the injury but can be improved with intervention. The challenge at this level is the client becoming aware of their deficits without being overcome and defeated by them.

Mastery

This challenge is met when a client has compensated for their cognitive deficits. Compensation can be achieved in two different manners. The first is by achieving satisfactory functional adjustment to a deficit. The other is the reacquisition of a certain function by directly strengthening the component skills in which the function was originally acquired. On a cognitive level, mastery is achieved by the deliberate and diligent practice of remedial exercises until the results are achieved. On the psychological end, mastery means the attainment of the feeling that one can again successfully solve problems in daily life, and that one is "competent" again.

Control

In regard to the psychomotor and cognitive end, control is defined as smooth execution of tasks on which the client was trained. Psychologically, control is experienced as being able to again concentrate, relatively effortlessly, on the idea behind an act and on its ultimate objective, rather than on the mechanics.

Acceptance

This is achieved when a client calmly accepts that further improvements on certain tasks may not be attained. Further, acceptance is defined by the ability to have an accepting attitude towards what is possible, and willingly letting go of what is desirable. Acceptance is measured by the client's feelings of life being valuable and worth living and can derive pleasure in the present life.

Identity

At the top of the pyramid and the last challenge is identity. While it is still yet to be established if all clients with severe head injuries can re-establish their ego identity, it is hypothesized that optimal and stable rehabilitation proves successful in reconstituting, at least some, of the client's ego identity. This challenge is attained when the client can refer to themselves as the "true me."

Social and Family Challenges

Brain injury can affect social interactions, relationships, roles, and one's community. We all have certain roles in our relationships. It might be as a co-worker, a parent, or a spouse. It is common after brain injury to see changes in these roles due to changes in physical or cognitive abilities or psychological difficulties. This can cause stress and strain on the relationships.

"Friends have disappeared. Some of those I thought would step up, haven't. It hurts. Others I never thought I could rely on, our 'peripheral' friends, have amazed me with their loyalty and kindness, and have become our family. I have lost friends, but I have made new ones; friends who know no other Glyni than the one I am now; who don't run away when I break down and cry, when I rage against the medical system, when I'm tired, frustrated, scared. And those new friends are such a gift." - Glyni

After brain injury, many people find that their social circles and communities have changed. Due to the busy rehab schedule, it may be hard to find time to spend with friends or loved ones. Often, people find they build new relationships with their new rehab therapy "community."

There are 4 Keys to Success in Rehabilitation: **Awareness and Understanding**, **Malleability**, **Mastery of Compensations**, and **Acceptance**. These are important steps in understanding and accepting the changes that have occurred in your relationships and social life which continue to occur as time passes following the brain injury. These changes often are not easily noticed or recognized until one returns to work, driving, and their "real" life outside of rehab.

Here are some strategies for families and other support systems to help set-up a loved one for success. Setting up a loved one for success in recovery will also help reduce potential stress and strain on a relationship:

- **Avoid planning too much in one day**
- **Rest before social events and activities**
- **Use the familiar; invite others to your home or a familiar restaurant so there is less for your loved one to have to orient to**
- **Avoid reminding your loved one of past abilities, focus on what they can do now**
- **Avoid arguments and stress; notice "triggers" and change or avoid topics/environments to support relaxation and calm**
- **Discuss with your loved one how much detail you will share with friends or family regarding things that have changed since the injury**
- **Ask your loved one how you can help rather than assuming you know what they need**
- **Remind your loved one of his or her strategies in a gentle and consistent manner**
- **Find new activities/hobbies you and your loved one can enjoy together**
- **Remember to praise your loved one for the progress they have made**

Involvement of the Support System

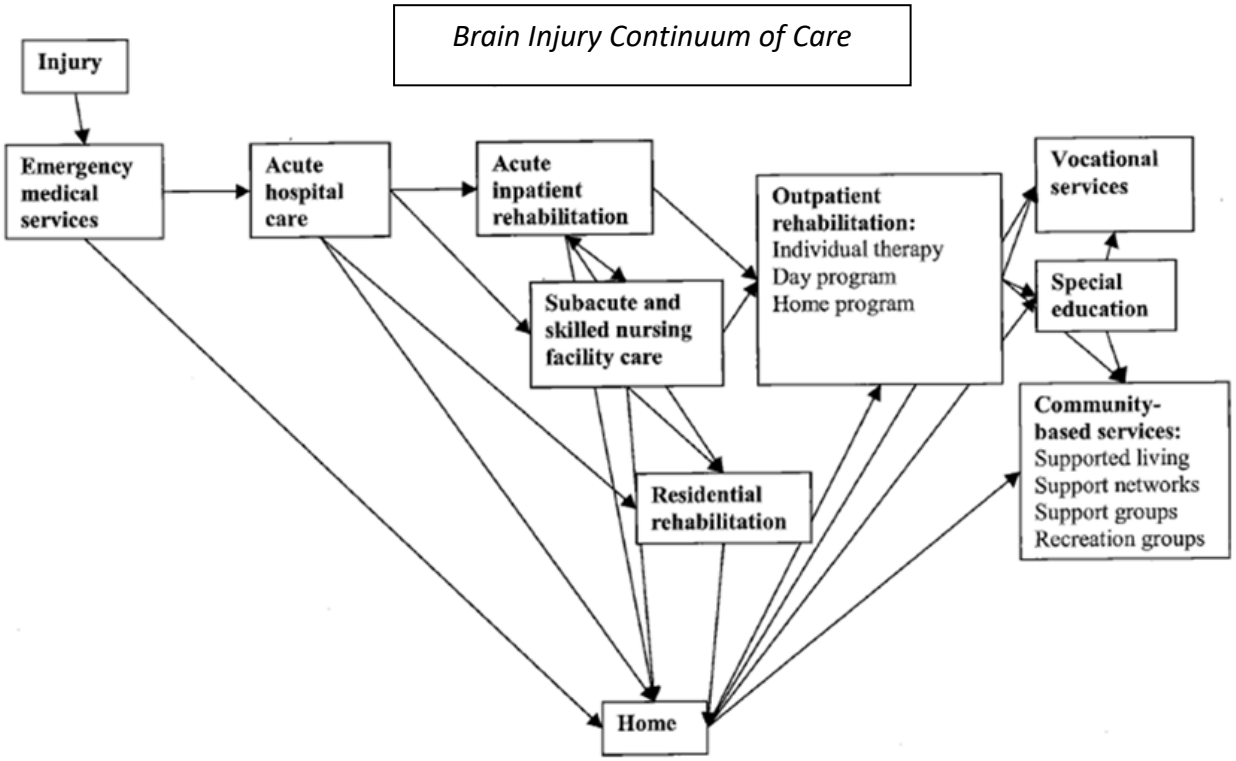
A support system may be comprised of the individual's spouse or significant other, family, friends, associates, co-workers, or religious group members. However, it is defined, the support system plays an essential role in the rehabilitation process. There are many changes physically, cognitively, and behaviorally that occur following brain injury. Individuals within the support system may be involved in several ways including, but not limited to:

- **Attend and engage in therapy sessions with the loved one**
- **Learn about the challenges facing the loved one**
- **Attend team meetings that discuss the rehab process and treatment planning**
- **Reinforce learned strategies and medical recommendations in the functional environment**
- **Assist with carrying out home exercise programs, as appropriate**
- **Attend local brain injury support and education groups**
- **Serve as an advocate with medical providers and funding sources, when needed**
- **Ask questions when clarification is needed**

The Rehabilitation Process

Continuum of Care

Depending on the severity of the injury, medical recommendations, supervision needs, and community resources, an individual may start at one point in the continuum of care and progress to other points throughout their given course of treatment. Therefore, an individual may not necessarily encounter certain points in the continuum of care, described in this section; in addition, a person may "skip" certain points in the continuum, depending on the individual needs.



Sub-Acute Rehabilitation

Following a medical hospitalization, an individual who is ready to begin participating in therapies, but continues to require medical treatment, would transition to a sub-acute rehabilitation center. Sub-acute rehabilitation centers continue to provide the necessary skilled medical care needs while the individual can begin participating in therapy.

Post-Acute Rehabilitation

Post-acute rehabilitation offers a combination of rehabilitation therapies such as physical, occupational, speech, recreational therapy, vocational, social work, and/or psychology services.

Depending on the program, each therapeutic discipline may have a variety of specialty service areas; examples include manual therapy, pre-driving skills retraining, vision therapy, and vestibular rehabilitation. Therapies are provided in several different points of the continuum including residential, community based, or outpatient.

Residential Rehabilitation Program

Residential rehabilitation programs may be short term rehab or long-term support for individuals who need specially designed services to achieve predicted outcomes focused on home and community integration and engagement in productive activities. Examples of productive activities are therapy, employment, volunteering, or schooling. Residentially based programs focus on the preparation or maintenance of functional, social and health needs.

"I progressed through the programs at Origami and have gradually become more independent. I was in the residential program for a while, outpatient and semi-independent living program where I lived in one of the apartments on campus. I now live in the community in an apartment of my own." -Jeff

Home and Community Services

Home and community-based programs services are supports provided in a variety of settings including, but not limited to, private homes, residential settings, schools, workplaces, community settings and health care settings.

Outpatient

Outpatient services are provided in a specialized rehabilitation center or clinic. An individual may need services from a single discipline or from an interdisciplinary team providing comprehensive treatment.

Goals of Brain Injury Rehabilitation

Everyone is unique in their presentation and deficits after brain injury. The goal of rehabilitation is to maximize function and encourage the survivor to attain their full potential. Each discipline on the rehabilitation team may have different goals pertaining to their specific discipline, but all goals are developed with the individual and family to achieve maximum potential. The individual is a part of the interdisciplinary team, and their personal goals should spear-head the rehab goals with compensatory techniques utilized as needed.

"I went to therapy to help me learn how to walk and talk again. I had to relearn how to perform basic personal care like brushing my teeth, shaving and getting dressed. I worked with a psychologist to deal with all the changes and emotional effects. Speech Therapy was my refreshing first sign of help! I learned new ways to do things that they referred to as 'strategies.' They educate me about the effects of traumatic brain injury." - Jeff

The Rehabilitation Team

Depending on the individual needs, a rehabilitation team may be composed of a single-service provider or a comprehensive multi-disciplinary group of professionals. For the purposes of this section, the individual that is receiving the services of the rehabilitation team will be called the "client."

Case Managers/Care Coordinators

A Case Manager assures the client receives the range of service needed. The Case Manager informs the client's insurance company of progress, helps plan the next stage of rehabilitation, talks with clients about personal and/or family concerns, coordinates family training and therapy, helps problem-solve and serves as a family's main point of contact and advocate when needed.

Certified Therapeutic Recreation Specialists (CTRS)

A CTRS assesses leisure skill interests and helps to discover ways to adapt these interests to a client's new lifestyle. They will also show clients how to minimize barriers in accessing the community; work on self-advocacy in the community and talk through issues that may make recovering individuals hesitant to return to previous activities. A CTRS may consult with a specialist in a client's area of interest such as gardening, sports, fitness, art, and dance. The specialists will further help you determine how to achieve leisure goals.

Dietitians

Injury, coma, and surgery often have significant impact on nutritional status. A dietitian will assess the current nutritional status, provide recommendations for achieving optimal health, and monitor progress of the client. In addition, the dietitian will provide education on topics such as maintaining a healthy body weight, role of fiber in the diet, prevention and treatment of skin wounds and diabetes.

Neuro-Visual Optometrists

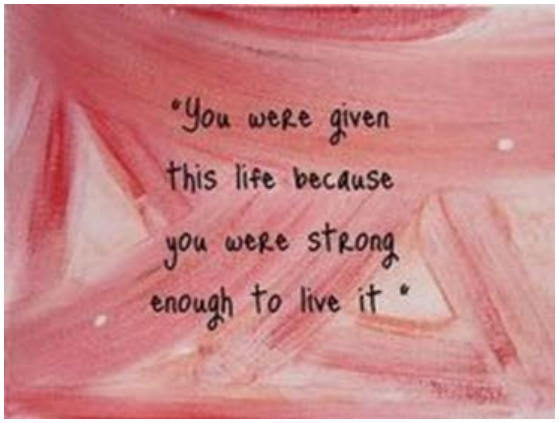
A Neuro-Visual optometrist is an optometrist that specializes in vision therapy and prism lenses. They focus on improving the flow and processing between the eyes and the brain. Neuro-Visual optometrists follow a holistic and functional approach to vision care looking at client behaviors, abilities, and relating them to visual skills. Neuro-Visual optometrists view vision as a learned sense

that may be improved or enhanced. This type of optometrist examines the visual system beyond the heath of the eye itself. Evaluations are extended to include tests beyond acuity, depth perception, and visual fields. A Neuro-Visual optometrist will determine how the eyes work together, focus together on a single object, process information, and move.

Nurses

Nurses specially trained in the treatment of brain injury may help guide medical treatment plans, manage medication, skin care, bowel, and bladder programs, and address any pain a client may be experiencing. A nurse will also evaluate health education needs and meet with clients and their family to discuss the injury.

Occupational Therapists (OT)



OTs access how much strength and physical sensation an individual has, focusing mostly on the arms, hands and trunk. Then, they will work with clients to regain daily living skills such as eating, grooming, dressing, driving, and job performance. Depending on a client's diagnosis, an OT may also teach clients how to provide bowel or bladder care. Clients will begin an exercise program to help with those skills. Clients may also work on visual and cognitive skills with an OT. An OT may also assist with equipment needs, computer access, return to driving plan and home safety recommendations according to the physical or cognitive needs of each individual. An OT may also work with the client to decrease any pain that may be experienced.

Physiatrists

A Physiatrist may be an attending physician who directs client care. They identify problems and prescribe medication and other treatment services. The physiatrist focuses on restoration of the body and mind after trauma has occurred. In some cases, the restoration is ongoing, and the goal is to teach clients how to live and cope with the effects of pain or lack of function and lead a full and productive life to the greatest extent possible. The physiatrist may also help establish rehabilitation goals, plan the discharge and approve any equipment a client will need after discharge/transition to the next point in the continuum of care.

Physical Therapists (PT)

These therapists will begin an exercise and therapy plan after evaluating movement, balance, muscle strength and range of motion, and pain. Clients may work on regaining functional independence so they can move from place to place, either in a wheelchair or by walking. A PT utilizes manual therapy skills to address musculoskeletal causes of pain, improve joint range of motion, and attain ideal bony and soft tissue alignment. Vestibular therapy is also addressed by a PT and will include exercises and treatment to improve a client's balance and vestibular system to decrease dizziness and vertigo. A PT may also work with clients and their family or caregiver to

determine appropriate equipment for safe transfers and mobility as well as any home exercise programs to assist in continued exercise to meet goals.

Psychiatrists

These are physicians who specialize in the evaluation and management of cognitive and behavioral aspects of brain injury. They will assist clients in identifying necessary services that will assist with recovery as well as establish a medication regimen if appropriate.

Psychologists

These professionals help clients and those important to them cope with feelings related to the many life changes that are caused by injury or illness. This may be accomplished through individual, group, and family counseling.

Social Workers

A Social Worker may assist in helping to connect the many aspects of the recovery process while considering the goals, desires, lifestyle, relationships, education and work history, and financial background of each client. These professionals identify the resources clients need within the community during rehabilitation and after discharge/transition to another point in the continuum of care.

Speech-Language Pathologists (SLP)

Clients who have memory, concentration, and language problems may work with a SLP. They may assist with daily skills such as organization and planning activities. Communication and social skills will also be addressed if changes have occurred. If the client has an artificial airway, the SLP may also help teach them how to talk on their own or with a special device. An SLP may perform tests to determine the cause of any hearing, chewing and swallowing problems and design treatment programs to help address these difficulties. SLPs may work closely with the dietician to make food choices if there are restrictions because of swallowing problems.

Vocational Services Specialists (VSS)

The VSS assists clients in meeting vocational and/or pre-vocational goals such as employment, school, and volunteer work. They assess job skills, interests, and identify reasonable accommodations to help a client successfully return to productive activity.

The Rehabilitation Process

Assessment → Goal Formation → Treatment → Goal Attainment and Evaluation → Transition/Discharge

Assessment

The rehabilitation process begins with assessments by the treating rehabilitation team member(s). The therapist or physician uses various types of methods to assess areas of strengths and deficits. Assessments are completed in various ways and locations. They can be completed through use of equipment, activities, pencil and paper testing, and/or through daily tasks that are meaningful. Locations can vary within a gym, office, home like setting or community.

Goal Formation and Treatment

The assessment results assist with developing measurable short term and long-term treatment goals. Goal formation also includes establishing predicted outcomes. Outcomes may include the length of stay in the setting, transition/discharge locations, long term resource needs, and functional capacity at discharge. Goal formation should be done together with the individual and their family/support system. Together, with the rehabilitation team, meaningful goals are set that dictate the direction of the subsequent treatment plan. Treatment frequency (hours/days per week) and duration (weeks/months) are dictated by the severity of the injury, results of the assessment, goal formation, predicted outcomes, and the developed treatment plan.

Goal Attainment and Evaluation

Throughout treatment the therapist will continue to re-evaluate progress towards achieving established goals. As short-term goals are met, evaluation of continued needed treatment takes place. Predicted outcomes are continually monitored to ensure accuracy and to adjust based on any new information or occurrences that may have transpired. Final evaluations may include functional demonstration of learned strategies, repeat testing, and/or verbal review of learned education.

Transition / Discharge

When goals have been attained and/or a plateau in progress has been reached, a discharge from treatment or a transition to the next point in the continuum of care will take place. Transition / Discharge planning occurs throughout the course of treatment, is considered when setting goals

and predicting outcomes, and should be done along with the individual and their family/support system, as appropriate.

Special Considerations

Life after Brain Injury

There are certain activities that individuals want to "get back to", which depends on the nature of the injury and the subsequent changes and challenges. The "Big Three Goals" – return to home, return to work/school, and/or return to driving – are often the major focus for individuals that have sustained an injury that has interrupted any of these areas. Everyone is unique, each circumstance special, and each injury different from the next; therefore, it is difficult to make blanket statements about the process to achieve these goals. However, there are certain things to consider when thinking about, and discussing, the "Big Three Goals."

Transitioning Home

Rehabilitation may begin in the hospital and can continue through inpatient rehabilitation and/or residential care. This process continues at home many times with outpatient services, which can last much longer than inpatient. The rehabilitation team develops rehabilitation goals with the individual and family members for increased success and independence. Initially there may be external care takers or a family member assisting in the home. Having realistic goals and re-evaluating these regularly is highly important for success. The number one focus with a transition to home is safety, and some restrictions may be recommended initially based on balance, strength, reaction times, and judgment. These restrictions will be evaluated continuously and reduced and/or eliminated as safety concerns reduce due to an improvement through the rehabilitation and recovery process.

Returning to Work or School

Depending on the severity and nature of the brain injury, individuals may return rather quickly to their previous vocation; however, brain injury can make it difficult to return to a previous level of work or school and some accommodations may need to be put into place. Sometimes a different route of work, volunteering, or school may need to be considered. A vocational specialist can work directly with the individual and support system to evaluate talents and areas

"At first, I got a job that required minimal thinking with a job coach. Once I learned the routine, I did well. I have advanced at work and was voted Employee of the Year. I have come to accept the fact that I can't drive. I don't want to risk hurting someone else if I have a seizure. I might get lost and confused, overwhelmed and irritated with other drivers. I now use Spec-Tran."
- Jeff

of need in relation to returning to productive activity. Considerations may include availability of jobs, health, neurofatigue, physical abilities, ability to adjust to changes, social or behavioral skills, thinking and problem-solving abilities, awareness of new deficits, receptiveness to feedback and training, and a willingness of employer to alter a job or workplace to accommodate needs. When returning to school, an **Individualized Education Plan (IEP)** or a **504 plan** can be initiated to receive accommodations including special education services to increase the likelihood of success.

Returning to Driving

Depending on the severity and nature of the brain injury, individuals may return rather quickly to driving; however, following brain injury a medical restriction from driving may be documented due to cognitive, physical, and/or visual deficits; or state laws related to loss of consciousness and/or seizure activity. If returning to driving is a goal, the rehabilitation team can work with the individual and family to set goals and complete pre-driving therapies when appropriate. When goals are met and if a person is determined to be safe to return, a behind the wheel evaluation and/or training with a rehab driving specialist may be recommended with final approval required by a treating physician. At times, restrictions may be recommended with approval to drive, such as a limited driving radius and on familiar routes, limiting distractions (no music, no children or other passengers, etc.), or driving during daylight and outside of rush hour traffic times.

For adults that wish to pursue driving but have never obtained a driver's license, a Temporary Instructional Permit (TIP) is required with logged driving hours with another licensed adulted prior to taking the on the road assessment to obtain a driver's license. Rehab driving specialists can assist in this process and provide recommendations on appropriateness to pursue a TIP and eventually license.

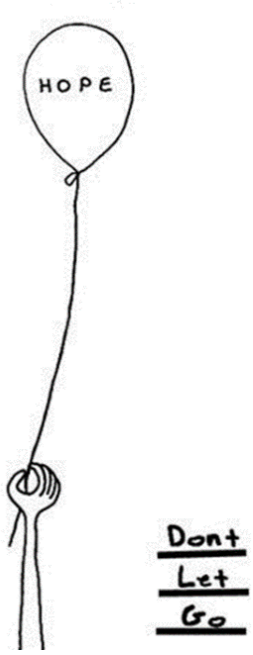
As individuals age, it is important that they, along with their close family/friends assess their driving abilities and safety. Potential warning signs for aging drivers include:

- Get lost while driving
- Trouble finding and reading signs
- Any recent car crashes
- Any feeling of tiredness, nervousness, fear, or sleepiness
- Medication makes them dizzy or drowsy
- Memory or cognitive changes within the home and/or during other functional tasks

Safe Drivers, Smart Options (Safe Drivers Smart Options (michigan.gov) is a useful resource with tools to help caregivers determine if a driving evaluation is necessary.

If driving is a long-term restriction, there are options for alternative transportation to meet daily needs. Michigan provides some transportation in all 83 counties. There are several urbanized public transit agencies across the state and several non-urbanized transit agencies. The Michigan Department of Transportation (MDOT) administers funding programs to these agencies. Specific information about local public transit services can be obtained by contacting MDOT's Passenger Transportation Division (phone number: 517-373-2090; website: www.michigan.gov/mdot).

Children and Adolescents



A unique approach must be taken when working with children and adolescents who have sustained brain injury. The impact of brain injury upon an adolescent differs from that of an adult as the child/adolescent is in a period of development. The adolescent's brain is still in a period of development in which the brain is maturing and changing rapidly. There is often damage to the brain systems after an injury, which are responsible for skill acquisition, or the ability to learn and develop new skills.

Professionals often classify adolescent brain injury as a "developing disability over time". Following brain injury or concussion, a child or adolescent may not demonstrate significant changes in thinking or behavior. However, over time, some of these changes may become more evident as the child returns to school and resumes social interactions. Often, the brain injury changes are noticed as learning demands increase and as children are developing more independent social skills, particularly when higher level thinking skills (executive functions) are required.

In addition to the other commonly occurring brain injury related challenges (i.e., memory, difficulties concentrating, mental fatigue), executive functions may be impacted, or not even developed yet, at the time of an injury. Executive functions begin to develop during adolescence and continue to mature into a person's early 20's. These skills impact communication and social skills, as they are involved in taking another's perspective, inhibiting distractions to stay on topic, and deciding whether a comment is socially appropriate. Adolescents who sustain brain injury prior to the development of such skills may appear "stuck" in the period of adolescent or teenage thinking. This can lead to both long- and short-term consequences in social and academic success.

A child's rehabilitation team will work closely with the teachers and administration at the child's school to assist the school in understanding how to best support the child. Brain injury education will be provided to those who work closely with the child regarding physical, cognitive, behavioral, or emotional changes associated with the injury, as well as strategies to help the child and parents navigate changes within the school setting. It is important for those working with a child to understand the signs of brain injury related changes, as often cognitive changes, such as difficulties focusing attention, may present as a behavioral problem. A 504 plan or Individualized Education Plan (IEP) may be recommended to promote a consistent approach to best meet the child's needs within an academic setting. Examples of possible accommodations are listed in the table below.

Examples of Possible Accommodations for a Child or Adolescent following a Brain Injury

Deficit Area	Possible Accommodations
Mental fatigue	Additional study hall throughout school day; quiet location to rest during lunch hour
Slowed processing speeds	Additional time to complete tests; Reader for test completion
Memory impairments	Use of planner to recall assignments and due dates; Record lectures to study later
Difficulties concentrating	Quiet room for test-taking; sit near the front of the classroom

Dementia and Brain Injury

Over the past 30 years, research has linked moderate and severe traumatic brain injury to a greater risk of developing **Alzheimer's disease** or another type of dementia years after the original head injury.

- One of the key studies showing an increased risk found that older adults with a history of moderate traumatic brain injury had a 2.3 times greater risk of developing Alzheimer's than seniors with no history of head injury, and those with a history of severe traumatic brain injury had a 4.5 times greater risk.
- Emerging evidence suggests that repeated mild traumatic brain injuries, such as those that can occur in sports like American football, hockey and soccer, may be linked to a greater risk of a type of dementia called chronic traumatic encephalopathy. Research has shown that boxers have an increased risk of chronic traumatic encephalopathy.
- Current research on how traumatic brain injury changes brain chemistry indicates a relationship between traumatic brain injury and hallmark protein abnormalities (beta-amyloid and tau) linked to Alzheimer's.
- Some research suggests that traumatic brain injury may be more likely to cause dementia in individuals who have a variation of the gene for apolipoprotein E (APOE) called APOE-e4. More research is needed to understand the link between APOE-e4 and dementia risk in those who've had a brain injury.

Family and friends may see early signs of Alzheimer’s disease in their loved ones, and this should be a cue to seek help.

Early signs of possible onset of Alzheimer’s disease

- Noting changes in memory, particularly a worsening of recall of previously learned tasks or events
- Greater problems with planning and problem-solving

- New difficulties with doing familiar tasks as driving, budgets, or cooking
- Greater confusion regarding time and place
- New problems with speaking, writing or reading
- Misplacing things and having difficulty retracing one's steps
- Withdrawal from work and activities

Aging with Brain Injury

Despite growing rates of brain injury in the elderly, our understanding of the consequences of brain injury in older people is limited. The long-term clinical course of brain injury appears to be variable, as some people experience accelerated decline, earlier onset of age-related diseases, or even death, while in others the course of aging is like younger adults. We do know that falls are the most common cause of brain injury in this age group, that older adults tend to have poorer post-injury outcomes than younger adults and that brain injury is associated with premature death. It is not known whether the decline seen in many elderly individuals with brain injury represents a continuation of a pre-existing disease process, possibly interacting with the effects of the brain injury, or if brain injury is the causal trigger in stimulating subsequent decline in a previously healthy person.

Brain injury may interact negatively with aging in at least two ways: (1) recovery after brain injury is more limited for older than younger survivors; and (2) older individuals who have suffered a brain injury are at higher risk for progressive cognitive decline. Advanced age at the time of injury may result in less complete recovery compared to younger persons with comparable injuries. While the mechanisms of this phenomenon are not known, it may be due simply to less capacity for compensation or reduced cognitive reserves, with increasing age.

Co-Morbid Disorders with Brain Injury

Several psychiatric comorbidities, particularly mood and anxiety disorders and substance abuse, have been associated with brain injury. The appearance of these behavioral symptoms and disorders is dependent on the physical, cognitive, and emotional deficits following brain injury, pre-morbid personality traits, and psychosocial environmental factors.

Mood Disorders

Rates (18.5% to 61%) of comorbid Major Depression and TBI vary widely and influenced by both pre-morbid factors and lesion location. The onset of symptoms following brain injury is also variable, with some patients meeting criteria for Major Depression at discharge, while others not meeting criteria for months or years later. The risk and severity of developing Major Depression is particularly high in the first 3-12 months following a traumatic brain injury and decreases with time from injury in the first 6 years post-injury. Other risk factors associated with brain injury and comorbid depression include socioeconomic factors, minority status, unemployment and low

income, history of psychiatric disorders and alcohol abuse, and less than 12 years of education. In general, patients receiving a dual diagnosis of both brain injury and Major Depression have much poorer outcomes relative to those diagnosed with brain injury alone.

Anxiety Disorders

Individuals with a TBI have higher rates (24.5%-44%) of Generalized Anxiety Disorder (GAD) and Post-Traumatic Stress Disorder (PTSD; 17%-33%) and a dual psychiatric diagnosis of TBI and GAD or PTSD is associated with poorer outcomes and course of recovery. The risk of a dual PTSD diagnosis is highest with mild and moderate injury when there may be a minimum of posttraumatic amnesia. Pre-injury factors associated with an increased risk of developing PTSD with brain injury include lower socioeconomic status, use of avoidance coping strategies, prior history of trauma or psychiatric problems, and limited social support. As seen more generally in treating brain injury, social support is the dominant moderating factor, such that increased social support is associated with decreased symptoms of psychiatric disorders, and improvement in long term survival and community integration.

Impulse Control Disorders

Brain injury may also result in some individuals developing impulsive behaviors or Impulse Control Disorders. This is particularly true when the damage has been to the frontal cortical areas of the brain and has been associated with high rates of substance abuse and risk-taking behaviors.

Alcohol and Substance Misuse

Alcohol use and brain injury are closely related. Up to two-thirds of people with brain injuries have a history of alcohol abuse or risky drinking. Between 30-50% of people with TBI were injured while they were drunk and about one-third were under the influence of other drugs. Around half of those who have a brain injury cut down on their drinking or stop altogether after injury, but some people with brain injury continue to drink heavily, which increases their risk of having negative outcomes.

After brain injury, many people notice their brains are more sensitive to alcohol. Drinking increases your chances of getting injured again, makes cognitive (thinking) problems worse, and increases your chances of having emotional problems such as depression. In addition, drinking can reduce brain injury recovery. For these reasons, staying away from alcohol is strongly recommended to avoid further injury to the brain and to promote as much healing as possible. This section provides specific areas of risk associated with alcohol misuse following brain injury and the rewards of abstaining from use.

Alcohol and Brain Injury Recovery

Risks and Rewards:

- Recovery from brain injury continues for much longer than we used to think possible. Many people notice improvements for many years after injury.
- Alcohol slows down or stops brain injury recovery.
- Not drinking is one way to give the brain the best chance to heal.
- People's lives often continue to improve many years after brain injury. Not drinking will increase the chance of improvement.

Alcohol, Brain Injury, and Seizures

Risks and Rewards:

- Traumatic brain injury puts survivors at risk for developing seizures (epilepsy).
- Alcohol lowers the seizure threshold and may trigger seizures.
- Not drinking can reduce the risk of developing seizures.

Alcohol and Subsequent Brain Injuries

Risks and Rewards:

- After a brain injury, survivors are at higher risk (3 to 8 times higher) of having another brain injury.
- Drinking alcohol puts survivors at an even higher risk of having a second brain injury. This may be because both brain injury and alcohol can affect coordination and balance.
- Not drinking can reduce the risk of having another brain injury.

Alcohol and Mental Functioning

Risks and Rewards:

- Alcohol and brain injury have similar negative effects on mental abilities like memory and thinking flexibility.
- Alcohol magnifies some of the cognitive problems caused by brain injury.
- Alcohol may affect brain injury survivors more than it did before their injury.
- The negative mental effects of alcohol can last from days to weeks after drinking stops.
- Not drinking is one way to keep mental abilities at their best and stay sharp and focused.

Alcohol and Mood

Risks and Rewards:

- Depression is about 8 times more common in the first year after TBI than in the general population.
- Alcohol is a "depressant" drug and using alcohol can cause or worsen depression.
- Alcohol can reduce the effectiveness of anti-depressant medications. People who are taking antidepressants should not drink alcohol.
- One way to improve problems with sadness or depression after brain injury is to stop or cut down on the use of alcohol.

Alcohol and Sexuality

Risks and Rewards:

- Lowered desire is the most common effect of TBI on sexuality.
- Alcohol reduces testosterone production in males.
- Alcohol reduces sexual performance (erection and ejaculation) in men.
- Alcohol reduces sexual satisfaction in men and women.
- Avoiding alcohol improves sexual ability and activity in men and women.

Intimacy and Sexuality

Less commonly discussed areas related to changes following a brain injury are those regarding intimacy and sexuality. Sexuality and experiences of intimacy are important contributors to quality of life and are important to build and maintain healthy relationships. Problems related to sexual functioning, relationship-building, and sexual expression is common following brain injury, however, are not often recognized until later in the rehabilitation journey.

"I want someone to share my feelings and experiences with. I want to build friendships, start dating, I haven't dated in 25 years! I don't want to be that hurt again, but I don't want to be alone. I want someone to love and be loved back and talk with and hold hands and kiss and snuggle and say 'I love you.' - Jeff

Discussion of issues related to intimacy and sexuality are often avoided due to uncomfortable feelings or fear of invading an individual's privacy. However, sexuality is an aspect of the human experience; this does not end after brain injury. Individuals and significant others should be encouraged to discuss these issues openly with physicians and the rehabilitation team; the expectation should be that these professionals welcome this discussion and are prepared to assist. Depending on the severity and nature of the brain injury, issues related to intimacy and sexuality may span a spectrum of challenges. This section provides an overview of possible challenges following brain injury and tips for the significant other.

Possible Challenges Following Brain Injury	Tips for Significant Other
• decreased or increased drive or desire for sexual activity • decreased arousal or sensation • sexual dysfunction (i.e., ejaculatory dysfunction, decreased fertility) • difficulties controlling emotional energy (disinhibition) or decreased emotional expression (adynamia) impact relationships	• share concerns and needs with treatment team so that sexuality and intimacy changes may be properly assessed • do not take disinterest personally • promote open communication about issues you both are having in an honest and open manner • avoid judgment over emotional

• cognitive difficulties (i.e., poor memory, decreased initiation, planning and reasoning difficulties, communication challenges) may affect the frequency of sexual encounters or ability to successfully identify and meet a significant others' relationship needs and expectations • emotional and behavioral changes (i.e., depression, low self-esteem, poor body-image, apathy, irritability, anger) may have a negative impact on sexual expression and intimate relationships • medications may impact several areas of sexual functioning and are important to discuss with a medical professional	connectivity or sexual performance • go at the pace of your partner • implement strategies and recommendations provided by treatment team • be sensitive to the experiences and feelings (frustration, anxiety, embarrassment) of your partner • celebrate progress and enjoy moments

Medical Complications

Depending on the severity and nature of the brain injury, as well as pre-injury health factors, individuals may face additional medical complications following the injury. The complications may be immediate or may present themselves weeks, months, or years after the injury. The complications may be short term and easily treatable or chronic in nature demanding constant attention and strategies to cope and manage appropriately. This section provides an overview of some medical complications that may be present after brain injury. This section does not list all possible medical complications; individuals and their support systems are urged to communicate with their physicians regarding any medical concerns that may seem new, or worsening, after brain injury.

Post-Traumatic Seizure Disorder/Epilepsy

Post-traumatic seizures are classified in three categories, immediate, early, and late. Immediate occurs within first 24 hours of injury. Early occurs 1-7 days post-injury. Late occurs greater than 7 days from injury. Post-traumatic epilepsy is when two or more late onset seizures are separated by a minimum of 24 hours and is not related to other causes such as infections or medications. Eighty percent (80%) experience their first seizure within the first year of the brain injury; while 90% experience their first seizure by the second year. The risk for post-traumatic epilepsy remains heightened for several years after a traumatic brain injury.

Types of Seizures

Generalized seizure: Originates on both sides of the brain. Includes the following:

- **Absence seizure:** Brief staring without movements. Shorter in duration; however, individuals may appear confused following the seizure.
- **Myoclonic seizure:** Sudden, brief, jerks of the body that have the appearance of muscle spasm.
- **Tonic-Clonic seizure:** Convulsions, rhythmic jerking of the body followed by confusion or feelings of sleepiness.
- **Atonic seizure:** Brief seizure that cause an unexpected fall to the ground.

Partial Seizure: Originates in one part of the brain. Includes the following:

- **Simple partial seizure:** Maintained in small area of the brain. Brief duration with normal awareness of surroundings; may include a brief jerk of extremity.
- **Complex partial seizure:** Maintained in one area of the brain but has spread to a large enough area which impairs awareness level. Presentation also includes staring without response, confusion, wandering, or fidgeting.

Spasticity

Spasticity is a state of increased muscle tone. There are several different types of treatment modalities used for spasticity including therapy, pharmacological and surgical interventions. Physical and/or occupational therapy perform stretching, splinting/casting and modalities using heat, ice, ultrasound, or electrical stimulation. Several different types of pharmacology interventions are possible, such as oral medications, injections, or procedural interventions such as placement of intrathecal Baclofen pump or tendon lengthening procedures.

Sleep Disorders

Sleep disturbances have a significant impact on rehabilitation, recovery and daily functioning. Sleep disturbances are classified as insomnia, hypersomnia, parasomnia and alterations of the sleep-wake schedule. Sleep disturbances are primarily caused by other medical issues such as depression and/or psychiatric conditions, pain, hormonal changes, sleep apnea, and narcolepsy. Treatments for sleep disturbances involve a combination of good sleep hygiene, nutritional and physical activity, and medications. Healthy sleep hygiene habits consist of setting aside time to relax at night, avoiding caffeine after 7:00 p.m., avoiding lights and sounds in the bedroom, and maintaining a consistent sleep/wake cycle. Medication measures that may be used in treating sleep disorders include **benzodiazepines, non-benzodiazepines, stimulants, antidepressants, antipsychotics and herbal supplements.**

Suspected Abuse and Neglect

Depending on the severity and nature of the injury, some individuals become more vulnerable to exploitation, abuse, and neglect after brain injury. Impaired decision making, disorientation, confusion, poor memory, or disinhibition could open the door for an individual with a brain injury to be taken advantage of. The Michigan Department of Human Services (www.michigan.gov/dhs) defines the following terms:

- *Vulnerable*: A condition in which an individual is unable to protect himself or herself from abuse, neglect, or exploitation because of a mental or physical impairment or advanced age.
- *Abuse*: Harm or threatened harm to an individual's health or welfare caused by another person. Abuse may be physical, sexual or emotional.
- *Neglect*: Harm to an individual's health or welfare caused by the inability of the individual to respond to a harmful situation (self-neglect) or the conduct of a person who assumes responsibility for a significant aspect of the individual's health or welfare.
- *Exploitation*: Misuse of an individual's funds, property, or personal dignity by another person.

If you suspect that you, or your loved one, is being exploited, abused, or neglected, you should contact your local authorities to file a report, or file a complaint with *Adult Protective Services* by calling *855-444-3911***.** This is a 24-hour available hotline; Adult Protective Services will follow up and initiate an investigation of the allegations within 24 hours.

Self-Advocacy and Communication with Medical Providers

"I love this man so much that I'll do whatever it takes for as long as it takes to get him the treatment and care he needs and deserves. I've kicked providers to the curb when I'm not happy with them; I'm up to three now. I am the squeaky wheel. I am known as Bill's Pit Bull. I was once told that I had to be polite, be pleasant, but be persistent! I don't mind bugging people to get Bill what he needs." - Glyni

The time immediately following a catastrophic or traumatic event can feel overwhelming. Time moves fast, people talk quickly, and medical jargon and terms are rattled off at a pace no lay person could keep up with. Emotions of fear and uncertainty adds to the anxiety; tack on some medical providers with poor bed-side manner, and it can almost be too much for one person to handle! However, although it may seem difficult, these are times when self-advocacy is most important.

The term self-advocacy has its roots in the disability rights movement. It is a term that is used to describe the process in which people with disabilities take control of their own lives and take charge of their medical care. Depending on the severity and nature of the brain injury, an individual may need support with self-advocacy from their loved ones who can speak on behalf of the best interest and wishes of the individual. Here are a few keys to effective self-advocacy and communication with medical providers:

- If you do not understand something, ask the provider to repeat the information until you do understand it.
- Request information in a format that matches your most effective learning style: in writing, verbal communication, physical demonstration, or a combination.
- If you have a different primary language than your provider, insist on an interpreter.
- Match your persistence with politeness; be tenacious, yet tactful.
- Request a second (or third) opinion if you are not satisfied with the first recommendation.
- Use resources (friends, family, reputable internet sources) to gather information that will help you with a decision.
- Do your homework and shop-around for post-emergency/acute care.
- Ask potential rehabilitation providers questions related to your individual goals and personal preferences.

Prevention

Some brain injuries are inevitable; however, precautions are possible is other situations. The more aware an individual is about the potential risk of injury, the more they will be able to make educated and possibly lifesaving decisions.

Here are some prevention strategies:

- Be aware of your surroundings
- Use caution when driving
    - Wear a seatbelt when traveling in a vehicle – driver or passenger
    - Don't text and drive
    - Don't drive under the influence
- Have the correct seats and safety belts for your baby or child
- Wear proper safety and headgear – helmets etc.
    - Riding a bike, motorcycle, snowmobile, electric scooter, or any all-terrain vehicle
    - Playing a contact sport, such as football, ice hockey, or boxing
    - Horseback riding
    - Skiing or snowboard
- Take extra precaution with older adults and children because fall risks are higher in these age groups
    - Older Adults:
        - Increase education on potential fall risks by discussing possible situations that could occur and what the response/action would be – important to recognize that falls are a normal risk of aging.
        - Maintain physical activity and weight bearing exercises to reduce the chance of losing muscular strength and endurance.
        - Provide ways for the individual to get in contact with someone if an accident occurs
            - Life Alert: medical alert system specifically designed to protect seniors and all family members in a home health emergency

        - InvisaWear: Safety devices that look like everyday accessories. By the push of a button on their device, it will send up to five family members an alert of assistance and their exact location
        - List emergency contacts on their phone
    - Review medication with doctor to see if any could increase dizziness, loss of balance, and/or sleepiness.
    - Have your eyes checked at least once a year and update necessary prescriptions.
    - Make the home safer:
        - Install handrails on bathroom walls, stairs, etc.
        - Remove tripping hazards like floor rugs
        - Improve lighting in the entire house
        - Use nonslip mats in the shower
- Children:
    - Maintain proper supervision in all environments.
    - Properly installed child car seats for their age range.
    - Wear proper safety gear and helmet during activities and spots.
    - Install window guards to keep children from falling out of open windows.
    - Use safety gates at the top or bottom of stairs.
    - Use gated play areas when they begin to crawl or walk, especially when they begin to pull themselves up by objects around them
    - Utilize playgrounds that have soft ground material to minimize the impact of a potential fall.

The most important aspect to prevention is to be mindful of your surroundings. Be alert to the potential risks around you and others and be prepared to respond is an accident does occur.

Supports and Resources

It is important for individuals with brain injury, and those that care about them, to know that they are not alone! There are community and civic groups as well as local and national organizations that have missions devoted to assisting individuals and families going through the journey of brain injury recovery and rehabilitation. Groups and organizations may have very specific focus areas such as education, advocacy, direct service and support, resource sharing, or connecting individuals with helpful organizations. This section identifies possible community supports and resources. The resources identified are not exhaustive of the possible supports located within one's community; the hope is to provide some examples and solid leads for the individual and/or support system to contact for further information and help.

"In group therapy, I learned about others with similar disabilities and deficits. We shared together ways that helped us manage and deal with them. Learning that my issues are 'real' and that there are ways to manage them has been extremely important." - Jeff

Community and Educational Resources

These organizations offer information and referral services for individuals with brain injury. They may serve as a good starting point for individuals looking for information on brain injury, locating resources in their home community, or deciphering the appropriate next step.

Brain Injury Association of America (BIA)
www.biausa.org
Phone: (703) 761-0750

Brain Injury Association of Michigan (BIAMI)
www.biami.org
Phone: (810) 229-5880

Disability Network Capital Area (DNCAP)
www.dncap.org
Phone: (877) 652-0403

Department of Human Services (DHS)
www.michigan.gov/dhs
Phone: (517) 887-9400 (Ingham County)

Capital Area Community Services, Inc.
http://www.cacs-inc.org/
Phone: (517) 393-7077

2-1-1 Get Connected. Get Answers
www.211.org
Phone: 2-1-1

Model Systems Knowledge Translation Center
http://www.msktc.org/tbi
Phone: (202) 403-5600

Michigan Department of Health and Human Services
http://www.michigan.gov/mdhhs/0,5885,7-339-71550_2941_4868_42176---,00.html

Advocacy Resources

These organizations offer information and/or services on matters related to consumer rights, civil rights, disability rights, and other legal matters.

Michigan Department of Civil Rights (MDCR)
www.michigan.gov/mdcr
Phone: (517) 335-3165

Michigan Disability Rights Coalition (MDRC)
www.mymdrc.org
Phone: (517) 333-2477

Michigan Protection and Advocacy Services (MPAS)
www.mpas.org
Phone: (800) 288-5923

Brain Injury Association of Michigan (BIAMI)
www.biami.org
Phone: (810) 229-5880

Auto No-Fault Insurance Resources

These organizations offer information and advocacy on issues specifically related to Michigan's auto no-fault system. It is important for accident victims and their support systems to know the benefits they are entitled to under auto no-fault system.

Coalition Protecting Auto No-Fault (CPAN)
www.protectnofault.org
Phone: (517) 882-1096

Michigan Association for Justice (MAJ)
www.michiganjustice.org
Phone: (517) 321-3073

Origami Rehabilitation

Origami's dynamic and innovative treatment team is ready to listen to your needs and guide you on the right path to recovery. With a commitment to providing clients and their families with a holistic approach to rehabilitation in a natural, healing environment, our specialized programs and services are designed to exclusively support recovery following neurological dysfunction.

Origami is a nonprofit organization offering residential and outpatient programs. Origami provides more than medical care. Origami works as a team, bringing together committed professionals who use a unique interdisciplinary approach and a network of community resources to meet the physical, social, spiritual, cognitive, and emotional needs of those served. Origami focuses on maximizing recovery, restoring quality of life, and independence.

Visit:	Call:	Email:
www.origamirehab.org	(517) 336-6060	info@origamirehab.org

Common Questions and Answers

You have been accompanied throughout this guide by Jeff and Glyni who have graciously shared parts of their story with you. Jeff and Glyni continue with their journey. While their journeys are unique to them, they share the knowledge and experience that may have led you to this brain injury guide. There are millions of people throughout the world who are united with Jeff and Glyni through the road to recovery after a brain injury; and they are united with you too!

"I am stronger than I ever thought possible—most of the time—because I've had to be. People don't see me when I'm tired, curled up in the fetal position, and sobbing, grieving for my best friend and the life we had together. I've learned to roll with what I've got and make it work for me, if I can't change it. It's a struggle sometimes—all of the time, in fact. My husband is a miracle; given his injuries, he's lucky to be alive, walking, and talking. And he kisses me back! I am thankful for that." - Glyni

This section contains some common questions and answers that many individuals and families may share along their road to recovery. If you have additional questions (and you most likely will), write them down and ask your medical and rehabilitation providers. If you are new to the journey and have yet to establish these relationships, utilize the resources located in the previous section to get the information you need to begin your road to recovery.

Q: How long will it take for me to be back to 'normal'?

A: The length of time for recovery is dependent on several factors including, but not limited to, the severity and nature of the injury, physical healing, engagement in a course of rehabilitation, and commitment to medical and rehabilitation goals and recommendations. It is impossible to make a blanket statement about timetables for recovery. Some deficits may resolve through healing and rehabilitation; and some may last a lifetime requiring compensatory strategies. Some individuals and families may find the need to redefine what 'normal' means and create a new healthy 'normal.'

Q: Will my spouse be able to return to his old job when he is done with his rehab?

A: A return to work is dependent on the severity and nature of the injury, prognosis for recovery, and the impact any residual deficits may have on the job responsibilities. Variables such as stamina, physical and mental fatigue, social behavior, decision making, and executive functions may determine if a return to work is possible and appropriate.

Q: Will I be able to get back to driving when I am done with rehab?

A: We take for granted all that goes into driving. We rely on impulses, reflexes, vision, coordination, memory, focus, and decision making every time we get behind the wheel. Safety must be the most important factor to consider when deciding if a return to driving is appropriate. Work in rehabilitation that focuses on the deficit areas that challenge the ability to drive safely may lead to a return to driving. However, it is a reality for some that a return to driving is not safe. In these instances, tapping into community resources for transportation may be necessary.

Q: My dad is so not himself. He is either angry or tired all the time. Will this last forever?

A: Behavioral, cognitive, and psychological deficits may resolve through focused rehabilitation and physical healing; or changes may last a lifetime. Concerned family members and other support systems need to be actively involved in the rehabilitation process so that they can be prepared to deal with such challenges and help the injured individual in the functional setting.

Q: How many hours of therapy should I expect once I am out of the hospital?

A: It is important to maximize whatever a person can handle early in the rehabilitation process. Early focused and intense rehab improves outcomes. The specific number of hours will depend on what the individual can tolerate, balancing rehabilitation with needed rest and healing. Therefore, an individual may have a treatment plan that includes 6 hours of therapy a day; while another individual may benefit from 3 hours of therapy a day with scheduled rest breaks in between sessions.

Glossary

Rehabilitation and Medical Terms

504 Plan: Written 'accommodation plan' to attempt to best remove barriers and allow students with disabilities to participate freely in an academic setting.

Abnormal tone: Muscle tone is the continuous and passive contraction of the muscles. After an injury, abnormally low (hypotonia) or high (hypertonia) muscle tone can result. Low tone will result in flaccid or floppy limbs. High tone presents with rigidity of muscles.

Absence seizure: Brief staring without movements. Shorter in duration; however, individuals may appear confused following the seizure.

Acceptance: A term to describe how well a person has accepted that the injury has happened and how it has changed their life. A person who demonstrates a healthy level of acceptance in rehabilitation is one who can talk about the injury without getting angry, he or she can demonstrate that they have hope for the future and can experience joy.

Acquired brain injury: An injury to the brain that has occurred after birth; these injuries are not a result of heredity, nor are they congenital or degenerative.

Alzheimer's disease: A progressive disease that destroys memory and other important mental functions.

Anoxia: Absence of oxygen supply to an organ.

Antibiotics: Medications used to control and eliminate infections.

Anticonvulsants: Medications used to control and prevent seizures.

Antidepressants: Medications used to alleviate symptoms of depression.

Anti-inflammatories: Medications used to control pain and inflammation.

Antipsychotics: A class of psychiatric medication primarily used to manage psychosis, in particular in schizophrenia and bipolar disorder, and are increasingly being used in the management of non-psychotic disorders.

Aphasia: The partial or total inability to produce and/or understand speech.

Apraxia: The loss or impairment of the ability to perform complex coordinated movements despite having the desire and the physical ability to perform the movements.

Ataxia: The inability to coordinate the movement of muscles. Ataxia may affect the fingers, hands, arms, legs, body speech, or eye movements.

Awareness and Understanding: A term to describe whether or not a person is aware of the differences following a brain injury. The most successful people in rehabilitation are the ones who are aware of the problems related to the brain injury and how those problems impact their daily functioning.

Benzodiazepines: Medications that act on the central nervous system, produce sedation and muscle relaxation, and lower anxiety levels.

Complex partial seizure: Maintained in one area of the brain but has spread to a large enough area which impairs awareness level. Presentation also includes staring without response, confusion, wandering, or fidgeting.

Concussion: Trauma to the head that induces an alteration in mental status (physical or cognitive abilities) that may or may not involve a loss of consciousness.

Confabulation: Production of fabricated, distorted or misinterpreted memories about oneself or the world, without the conscious intention to deceive.

Coup-Contrecoup: An injury to the brain that occurs when an impact or violent motion brings the head to a sudden stop, causing injury to the impact site and the opposite side of the brain.

Disinhibition: A syndrome marked by difficulty properly directing and controlling energy and emotions.

Diplopia: Seeing two images of a single object; double vision.

Dysarthria: Difficulty in forming words or speaking them because of weakness of the muscles used in speaking. Tongue movements are usually labored and the rate of speaking may be very slow. Voice quality may be abnormal, volume may be weak, and/or drooling may occur.

Dysphagia: Difficulty swallowing.

Emotional Lability: A condition of excessive emotional reactions and frequent mood changes.

Executive Functions: The decision-making and planning processes invoked at the outset of a task and in the face of new challenges (Singer & Bashir, 1999). Referring to one's ability to utilize their knowledge effectively. May include prioritizing, sequencing, self-monitoring, reasoning, and altering behavior.

Generalized seizure: Seizure type that originates on both sides of the brain. Includes: absence, myoclonic, tonic-clonic, and atonic seizures.

Herbal supplements: Non-pharmaceutical, non-food substances marketed to improve health.

Hypoxia: Decreased oxygen levels in an organ.

Individualized Education Plan (IEP): A formal, written plan which guides the delivery of special education supports and services for the student with a disability. The IEP is developed by a team that includes the student's parents and school staff, with input from rehabilitation professionals.

Malleability: The ability to be flexible, moldable, open to feedback and change. The most successful people in rehabilitation are those who accept feedback from others and are open to trying things a new way.

Mastery of Compensations: Utilizes compensations and strategies consistently and effectively. Strategies become almost automatic because the individual practices them so often.

Mild Traumatic Brain Injury (mTBI): Trauma to the head that is characterized by, but not limited to, a loss of consciousness for less than 30 minutes, post-traumatic amnesia lasting for less than 24 hours, and a Glasgow Coma Scale of 13-15.

Moderate Brain Injury: Trauma to the head that is characterized by, but not limited to, a loss of consciousness for more than 30 minutes but less than 24 hours, post-traumatic amnesia lasting for more than 24 hours but less than 7 days, and a Glasgow Coma Scale of 9-12.

Muscle Relaxants: Medications that relieve muscle spasms and tightness.

Myoclonic seizure: Sudden, brief, jerks of the body that have the appearance of muscle spasm.

Neuron: A nerve cell that can receive and send information by way of connections with other nerve cells.

Neurotransmitter: Chemicals found within the brain that are released from a neuron which transmit signals from neuron to neuron across gaps called synapses. These chemicals either excite or inhibit specific reactions.

Nystagmus: Involuntary, usually rapid movement of the eyeballs (side to side or up and down).

Neuroleptics: Medications used to decrease agitation, hyperactivity, hallucinations, hostility and other psychotic symptoms.

Non-benzodiazepines: A class of psychoactive drugs that is very benzodiazepine-like in nature. Non-benzodiazepines pharmacodynamics are almost entirely the same as benzodiazepine drugs and therefore employs similar benefits, side-effects, and risks.

Oculomotor: Of or relating to the motion of the eye.

Paralysis: Loss of muscle functions for one or more muscles.

Partial seizure: Seizure that originates in one part of the brain, includes simple partial and complex partial seizures.

Seizure: Uncontrolled electrical activity in the brain, which may produce a physical convulsion, minor physical signs, thought disturbances, or a combination of symptoms. Seizures fall into two main groups. Focal seizures, also called partial seizures, happen in just one part of the brain. Generalized seizures are a result of abnormal activity throughout the brain.

Severe brain injury: Trauma to the head that is characterized by, but not limited to, a loss of consciousness for more than 24 hours, post-traumatic amnesia lasting for more than 7 days, and a Glasgow Coma Scale of 3-8.

Simple partial seizure: Maintained in small area of the brain. Brief in duration with normal awareness of surroundings; may include a brief jerk of extremity.

Spasticity: State of increased muscle tone.

Strabismus: Abnormal alignment of the eyes.

Stimulants: Psychoactive drugs that induce temporary improvements in either mental or physical functions or both. Examples of these kinds of effects may include enhanced alertness, wakefulness, and locomotion, among others.

Traumatic brain injury (TBI): An injury to the brain caused by an outside force which is sudden and traumatic in nature.

Tonic-Clonic seizure: Convulsions, rhythmic jerking of the body followed by confusion or feelings of sleepiness.

Vestibular system: The sensory system that provides the sense of movement, balance, and special orientation.

Insurance Terms

Health Insurance Terms

The terms located in this section are not exhaustive and do not include all of the possible nuances and intricacies associated with an individual's health care plan. Nor does this section include definitions and examples of specific types of health insurance plans. The consumer is recommended to contact his/her insurance provider for specific details associated with his/her insurance plan. The goal of this section is to provide broad definitions about certain health insurance terms that are important to know in any health insurance plan and terms which the consumer may hear in discussions with provider offices. Term definitions are taken from the United States Department of Labor Statistics.

Coinsurance: A form of medical cost sharing in a health insurance plan that requires the consumer to pay a set percentage of medical expenses after the deductible amount, if applicable, is paid.

Copayment: A form of medical cost sharing in a health insurance plan that requires the consumer to pay a fixed dollar amount when a medical service is received. The insurer is responsible for the rest of the reimbursement.

Deductible: A set dollar amount during the benefit period (usually a year) that a consumer pays before the insurer starts to make payments for covered medical services. Plans may have both per individual and family deductibles.

Maximum plan dollar amount: The maximum amount payable by the insurer for the covered expenses for the consumer and each covered dependent while covered under the health plan. Plans can have a yearly and/or a lifetime maximum dollar amount.

Maximum out-of-pocket expense: The maximum dollar amount a consumer is required to pay out of pocket during a year. After the maximum is reached, the insurer pays all covered expenses, up to the lifetime maximum.

Premium: Agreed upon fees paid for coverage of medical insurance benefits for a defined time period. Premiums can be paid by employers, unions, employees, or shared by both the consumer and the plan sponsor.

Type of health provider arrangements:

- **Exclusive providers:** Consumers must go to providers associated with the plan for all non-emergency care in order for those costs to be covered.
- **Any providers:** Consumers may go to providers of their choice with no cost incentives to use a particular subset of providers.
- **Mixture of providers:** Consumers may go to any provider but there is a cost incentive to use a particular subset of providers.

Michigan Auto No-Fault Insurance Terms

It is important for consumers to understand that there is the potential of two separate insurance claims resulting from an automobile accident in Michigan. A *tort liability claim* is for certain damages when someone else is at fault. A no-fault *personal protection insurance (PIP)* claim includes four distinct benefits that will be explained within this section. For the purposes of this guide, tort liability claims will not be discussed. The consumer is encouraged to contact an attorney to discuss all claims that may exist after an automobile accident. The terms in this section are broad in nature with the goal of providing a basic overview of key elements of PIP benefits and auto no-fault terms to know. The consumer, and/or their loved ones, is encouraged to contact support for further information on consumer rights and legal entitlements under the Michigan's auto no-fault law. Resources for help with auto no-fault can be found in the Advocacy Supports section of this guide.

Allowable Expense Benefits: All reasonable charges incurred for reasonably necessary products, services, and accommodations for an injured person's care, recovery and rehabilitation. These are lifetime benefits with no limit on dollar amount. These benefits may include, but are not limited to, medical expenses, in-home care, guardianship expenses, independent case manager services, assistive technology, special transportation needs, mileage to and from medical appointments, supervision, residential rehabilitation, and vocational supports.

PIP Options: Consumers may choose their level of coverage for medical expenses. Based on their choice of coverage, costs of allowable expenses reimbursed through the consumer's auto insurance policy are capped at this level. Options include (per covered person, per accident):

- Complete opt-out (for Medicare recipients or consumers with qualified health insurance plans)
- $50,000 (for Medicaid recipients only)
- $250,000
- $500,000

- Unlimited lifetime coverage (with no monetary cap)

Coordination of Benefits: It is important for consumers to understand what type of no-fault PIP benefits they have – *Coordinated* or *Uncoordinated*. The type of benefits will determine who is primarily responsible for payment of medical expenses after a motor vehicle accident.

- **Coordinated Benefits:** Traditional medical health insurance is the primary payer source (except for certain federal programs) for medical expenses. The auto insurance acts as the secondary payer source, paying for services not payable under the health insurance plan and/or when the plan's maximum plan dollar amount has been reached.
- **Uncoordinated Benefits:** Auto insurance is the primary payer source, responsible for all medical expenses associated with the PIP benefit claim.

Replacement Services: Expenses (up to $20 per day) for reasonably necessary services that the injured person would have performed prior to the injury, but can no longer perform, for up to three years post-injury. The intent of this benefit is for household duties such as housekeeping, lawn care, snow removal, and pet care.

Survivor's Loss Benefit: Payable for up to three years to the dependents of an individual that dies because of a motor vehicle accident. Benefits cannot exceed the legal monthly maximum. Primarily consists of the post-tax income of the person that died, the value of any fringe benefit lost, and replacement services. In addition, the benefit pays for funeral and burial expenses within the legal monthly maximum.

Wage Loss Benefits: Loss of income from work an injured person would have performed if he or she had not been injured. Payable at the rate of 85% of gross pay, including overtime, for up to three years post-injury; however, the benefit cannot exceed the legal monthly maximum. Wage loss is also available to injury persons who were temporarily unemployed from full-time employment at the time of the injury.

Utilization Review: A system in which insurers perform internal reviews of treatment utilization (appropriateness and duration) and cost. If an insurer denies reimbursement for services rendered based on their internal review, the consumer and/or provider may submit an appeal of the determination to the Michigan Department of Insurance and Financial Services.

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