
Traumatic Brain Injury (TBI) and the Impact on Daily Life

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Traumatic Brain Injury

Each year, an average of 1.7 million people sustain a traumatic brain injury (TBI) in the United States as a result of falls, motor vehicle accidents, sports injuries, assaults, blows to the head, or other injuries (Center for Disease Control and Prevention [CDC], 2015). Of this number, an estimated 43.3 % of Americans have residual disability 1 year after injury (Corrigan, Selassie, & (Langlois) Orman, 2010). The CDC (2015) estimates that 3.2–5.3 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result of a TBI. Direct medical costs and indirect costs such as lost productivity of TBI totaled an estimated \$76.5 billion in the United States in 2010 (CDC, 2016). TBI can be classified as mild, moderate, and severe.

Mild TBI

Approximately 80 % of TBIs are mild. A person with a mild TBI or concussion may remain conscious but appear confused. In some cases, there is a brief loss of consciousness for a few seconds or minutes. Brain scans such as an MRI or CT scan may be normal. Common signs and symptoms of a mild TBI include headache, dizziness, nausea, fatigue, irritability, sensitivity to noise, light, or busy environments and difficulties in concentration and thinking. In most persons, these symptoms are expected to resolve within 3 months but it is estimated that approximately 7–33 % of persons continue to experience significant symptoms

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that persist and significantly disrupt daily functioning (Shenton et al., 2012). Mild TBI can easily be overlooked or go unrecognized until the person experiences difficulty doing their everyday activities.

Tim was hit by a car while riding his bicycle. He was confused and dazed after the accident but witnesses state that he did not lose consciousness. He suffered a fractured elbow and ankle as a result of the accident and required orthopedic surgery. The first couple of months focused on his physical recovery and rehabilitation. After 10 weeks he returned to his job as an accountant but found he could not function. He was unable to prioritize, and mixed up client names and conversations. His co-workers wondered if he was having a nervous breakdown. They saw drastic changes in his work performance but there were no visible signs that anything was wrong. He did not immediately connect his difficulties to the accident. Co-workers didn't understand why he asked the same question over and over or why he always seemed like he was in a fog. He gradually became more and more withdrawn, isolated and depressed. He received a poor performance evaluation, was put on probation at work and was on the verge of getting fired. He didn't understand what was wrong.

This scenario is typical of persons experiencing mild brain injury. Symptoms may not appear until weeks following the injury or may even be missed as people may look fine even though they may be experiencing hidden cognitive difficulties in thinking, concentration, memory, reasoning, and emotional control. The word “mild” is deceiving as it leads one to believe that the problems are inconsequential when in reality, the problems resulting from a mild brain injury can have significant and far reaching effects.

Moderate–Severe TBI and Early Stages of Recovery

Persons with moderate to severe TBI, often lose consciousness for an extended period of time, lasting hours or weeks after an injury. Sometimes a person is quickly placed into a medically induced coma to reduce brain swelling. While a person is in a coma, appropriate positioning and range of motion of limbs is important to prevent later complications due to changes in muscles and ligament elasticity. Joints in the person's limbs can become stiff and contracted. As a person emerges from a coma they often progress through several stages during the recovery process. For example, immediately following a coma, disorientation, agitation, and confusion are frequently observed. The person may try to remove restraints, tubes, or get out of bed without a goal or purpose. Verbalizations may be inappropriate or incoherent and the person may not recognize family or friends or realize that they are in a hospital. Attention may be limited to less than a minute and objects are often used inappropriately. As agitation begins to subside, the person may be able to participate in familiar routine activities, although performance may be limited by confusion and decreased attention as well as physical or sensory difficulties.

Suggested Strategies for the Acute Phase

To facilitate attention and maximize performance during the phase of confusion and limited attention, the following suggestions may be helpful. See Table 6.1 for additional management strategies for cognitive behavioral problems.

1. Personal and familiar items can be brought to the hospital to stimulate past memories and help orient the person to place and time. Examples include favorite music, labeled photos, and recorded messages from family members.
2. Goal-directed, familiar, and purposeful functional tasks that are simple, rote, and repetitive can stimulate attention. Simple tasks such as combing hair, pouring water into a cup, eating, washing face with a washcloth, or drinking from a cup, should be encouraged.
3. Gentle physical guidance could be used during simple tasks (combing hair) to assist the person in performing the activity. Gradually, guidance is withdrawn, until the person performs the motion themselves.
4. Limiting the number of items placed in front of the person at one time will facilitate attention. For example, during eating, it may be best to have only 1 type of food on a plate. All other food, utensils, cups, etc. should be removed from the food tray. Too many items presented at once can create confusion, because the person does not know where to focus.
5. A quiet, structured environment is often needed to enhance performance. Thus, the number of visitors at any one time may need to be limited and distractions in the environment may need to be removed.
6. Short and concrete instructions with emphasis on key words will enhance communication and performance.

Difficulties in routine daily activities (feeding, grooming, and dressing) may be less observable after the period of confusion subsides and attention improves. The person may learn to function independently within the structured hospital setting but may continue to experience significant cognitive, physical, and emotional difficulties as described later in this chapter. Different types of problems can gradually emerge as the person returns home and tries to resume previous levels of function. In the early stages of recovery, the person has stopped working and family members and friends are often there to assist. In addition, a hospital setting provides a structured environment where others are there to provide cues and support, therefore the full extent of cognitive difficulties can be masked. It is not until a person tries to fully resume former roles and complex activities that difficulties in these areas may begin to become apparent.

A TBI, whether mild or severe, can result in physical, sensory, language, emotional, or cognitive problems that limit participation in everyday life. The next section reviews these different problems and their impact on daily functioning in greater depth. Since cognitive symptoms are the most frequent and disabling symptoms, greater emphasis will be given to this area.

Table 6.1 Management strategies for cognitive-behavioral problems

Problem areas	Problem observations <i>person may ...</i>	Management strategies <i>caregivers and staff should ...</i>
Confusion and disorientation	<ul style="list-style-type: none"> • Misinterpret information or be fearful in the environment • Be confused about time, day, present location • Yell out of fear or frustration 	<ul style="list-style-type: none"> • Use familiar and functional tasks that are simple, routine, and repetitive such as washing face, combing hair, etc. • Provide wall calendars, clocks, and written reminders to orient to time and place • Limit the number of visitors and distractions (e.g., radios, TVs, etc.) • Simplify tasks by providing step-by-step instructions and only objects needed to complete each step
Reduced initiation	<ul style="list-style-type: none"> • Fail to carry out verbalized plans • Lack spontaneity or drive • Show limited interest in engaging in activities • Appear passive • Have difficulty generating ideas 	<ul style="list-style-type: none"> • Use gentle physical guidance to help the person get started on a task • Provide structured directions • Establish a fixed routine • Use technology aids such as text messages, vibrating cell phones or pocket alarms to cue person to initiate tasks
Filtering information	<ul style="list-style-type: none"> • Appear not to listen • Have difficulty filtering information • Be unable to “multitask” • Miss details • Have difficulty prioritizing • Forget what people have said • Have difficulty concentrating • Be only able to cope with one thing at a time • Be easily sidetracked or distracted • Change the subject often • Not complete what they say or be “long winded” • Become easily bored 	<ul style="list-style-type: none"> • Use short, simple sentences • Keep activities short • Ensure the person writes down important information • Assist the person to monitor and check work for errors • Encourage the person to engage in and complete one activity at a time • Reduce external distractions (noise, people) • Limit the number of items in tasks and/or only provide objects needed for next task step • Bring the person’s focus back to task • Change activities to maintain interest

Pacing speed of response	<ul style="list-style-type: none"> • Take longer to complete tasks OR rush to complete tasks and make numerous errors • Take longer to gather thoughts and respond • Appear impulsive or disinhibited • Be unable to keep track of lengthy conversations or multiple step instructions 	<ul style="list-style-type: none"> • Give the person extra time to respond or complete tasks • Speak clearly and at an even pace • Present only one thing or directional step at a time • Try not to interrupt the person • Re-direct the person to the task or conversation • Use touch to cue the person to slow down or speed up
Inflexibility or “getting stuck”	<ul style="list-style-type: none"> • Be unable to accommodate for, or adapt to change • Become “stuck” repeating actions or tasks • Be unable to shift to new tasks • Persist with incorrect methods despite feedback 	<ul style="list-style-type: none"> • Assist the person to identify signs of frustration and stop what they are doing • Provide alternative ways of completing a task so a choice is available • Direct the person to another activity if they are continually making errors • If they are talking off topic, direct the person back to task by asking specific questions
Visual perception	<ul style="list-style-type: none"> • Misidentify, omit, fail to locate, align or position objects accurately • Skip over letters or words or misread letters when reading • Misuse objects that look similar • Have difficulty in functional tasks that require spatial placement such as dressing or object assembly • Pay unequal attention to both sides of the environment and neglect objects on one side (typically the left) 	<ul style="list-style-type: none"> • Place a bright object or the person’s arm on the neglected side of the task • Use bright tape to outline or surround key portions of task or object • Present information in a limited and organized structure • Keep visual space uncluttered • Use a small paper or plastic guide to assist scanning during reading • Place objects or clothing in the spatial orientation needed to complete task

(continued)

Table 6.1 (continued)

Problem areas	Problem observations <i>person may ...</i>	Management strategies <i>caregivers and staff should ...</i>
Losing track of information ^a	<ul style="list-style-type: none"> • Have difficulty following instructions or conversations • Lose track of what they are thinking, doing, or saying • Get information mixed up or become confused • Repeat errors or steps 	<ul style="list-style-type: none"> • Keep activities and instructions short and uncomplicated • Ask specific or direct questions • Provide reminders and checklists to the next step in a task
Remembering information over time ^a	<ul style="list-style-type: none"> • Forget conversations, names, appointments • Have difficulty learning new things • Lose or misplace things • Have difficulty recalling what they learned 	<ul style="list-style-type: none"> • Repeat information as necessary • Provide cues and reminders to help recall • Encourage rehearsal of new information • Encourage use of external memory aids; diaries, calendars, time tables • Use electronic devices such as cell phones, PDAs, and computers to cue memory and hold information • Maintain designated places to organize objects
Planning and organizing ^a	<ul style="list-style-type: none"> • Have difficulty preparing for a task • Take a haphazard approach to tasks • Be unable to work out the steps or sequence involved in a task • Lose track of the task goal and become side-tracked • Not consider the consequences of their actions • Have problems organizing their own thoughts and explaining things to others 	<ul style="list-style-type: none"> • Encourage the person to consider what they are about to do before commencing an activity • Provide a written structure or guideline outlining the steps in order • Give prompts or steps • Help develop a timetable (weekly, daily) to establish a routine of activities • Keep the environment organized so items are always kept in the same place • Encourage the person to take time to think about what they want to say

<p>Problem solving^a</p>	<ul style="list-style-type: none"> • Have difficulty working out solutions to problems • Be unable to generate new or alternative ideas • Have a disordered approach to problem solving 	<ul style="list-style-type: none"> • Help identify an achievable outcome for the task, ensure there is a purpose • Avoid giving open-ended tasks • Help the person to approach tasks in a more systematic manner • Assist the person to break a task down into smaller components • Reduce the demands made upon the person (one thing at a time, start simple)
<p>Reasoning^a</p>	<ul style="list-style-type: none"> • Have a rigid and concrete thinking style • Take statements literally • Fail to “put themselves in another’s shoes” • Be resistant to change • Have a simplistic understanding of emotions • Show poor judgment and poor decision making skills 	<ul style="list-style-type: none"> • Use simple and direct language and avoid talking in abstract terms • Explain changes in routine in advance, giving reasons • Try not to get into arguments with the person • Avoid using emotional undertones • Provide real life examples (preferably the person’s) when offering explanations
<p>Mental fatigue^a</p>	<ul style="list-style-type: none"> • Tire quickly during mental effort • Have reduced tolerance and ability to cope • Easily become irritable, anxious, or agitated • Be overwhelmed and become “frozen” or “shut down” • Have their other problems exacerbated 	<ul style="list-style-type: none"> • Encourage the person to take rest breaks • Schedule more demanding or essential tasks when the person is at their best (often morning) • Arrange activities to be shorter where there is an achievable goal

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Table 6.1 (continued)

Problem areas	Problem observations <i>person may ...</i>	Management strategies <i>caregivers and staff should ...</i>
Self-monitoring ^a	<ul style="list-style-type: none"> • Show poor adherence to rules • Not realize they have made errors because they have not checked their work • Monopolize conversations • Be verbose and keep talking when others are no longer interested 	<ul style="list-style-type: none"> • Reinforce specific requirements of an activity • Encourage the person to check over their work • Provide checklists to structure monitoring • Immediately indicate, or provide feedback, when errors occur or when the person talks too much • Use signals, which have been agreed to in advance, to let them know they are talking too much • Encourage turn taking in conversations
Awareness ^a	<ul style="list-style-type: none"> • Be unaware of cognitive and physical limitations • Recognize mismatch between task demands and skills only when problems are encountered • Set unrealistic goals, plans, and expectations • Be resistant to the effort of caregivers/staff 	<ul style="list-style-type: none"> • Ask person to state task goal and possible problems prior to beginning task • Provide explanation why proposed action (not the person's own plan) is useful, and reason through the steps (small steps, start gradually etc.) • Help to identify realistic goals—these may be smaller components of a larger plan, but more achievable
Language	<ul style="list-style-type: none"> • Have difficulty speaking, reading, or writing • Have difficulty understanding spoken or written words 	<ul style="list-style-type: none"> • Simplify sentences • Use gestures, point, or touch to help • Allow increased time • Use alternate communication methods such as pictures or technological aids • Consult with the speech-language pathologist for additional suggestions

^aSections adapted with permission from *Working with People with Traumatic Brain Injury*. Developed by the Brain Injury Rehabilitation Directorate, South Western & Southern Sydney Area Health Service Training. http://www.tbistafftraining.info/SelfStudy/Module_4/4.0.htm

Specific Symptoms

Physical and sensory changes: TBI can cause a wide variety of changes in sensation, movement, balance, or coordination, depending on the area of the brain that is affected. Sensory changes can include decreased sense of touch, smell, or taste. There may be a ringing sensation in the ears, blurriness of vision, double vision, and loss of depth perception. In some cases, peripheral vision to one side may be diminished or lost.

Physically, paralysis, incoordination, or weakness on one or both sides of the body can occur. Balance may be affected and the person may need to use an assistive device such as a cane or walker to walk safely. Manipulating small objects, picking up coins, buttoning, or zipping can be extremely effortful. Some people make an excellent physical recovery after a brain injury, which can mean there are few observable signs that an injury has occurred. There are often physical problems present that are not always so apparent, but can have a real impact on daily life. Those that appear to have made a good physical recovery may find it difficult to engage in physical activities because of fatigue, dizziness, headaches, or distorted perceptions. For example, depth perception may be disturbed and the person may feel less secure in their surroundings. The person may misjudge the space around them. Objects that appear to be distant may be close and the person may bump into objects, misjudge the height of a step, or appear clumsy. Crowded environments may be difficult to navigate. The person may be at greater risk of losing balance or falling when there are a lot of distractions in the environment or when they need to quickly change direction of movement.

These physical changes can result in disruption of roles and routines. The person may not be able to manage everyday household chores such as emptying the dishwasher, taking out the garbage, shopping, and cleaning. A parent may no longer be able to engage in sports or bicycle riding with their children. Subtle changes in physical skills can also impact the ability to work, depending on the physical requirements of the person's job. The inability to resume former roles and responsibilities can result in depression, anxiety, and a lost sense of self. If physical changes are accompanied by cognitive changes, it further compounds difficulties as well as the recovery process. For example, it may be difficult to learn important physical exercises and do them independently. Physical and occupational therapists can help survivors and their families in addressing the physical and sensory changes that can occur after an injury.

Changes in language abilities: Difficulties that affect the ability to speak and understand others are observed with injury to areas of the brain responsible for language. This is termed "aphasia." Some people with aphasia have difficulty finding or using the right words in sentences (i.e., expressive aphasia). Persons with TBI may say words in the wrong order, substitute words with different meanings, use profanity unintentionally, use a single word repetitively, or say a word that does not make sense. Speech is described as nonfluent as it is often limited to halting single words. The person may understand everything that they hear or read but cannot express themselves verbally or in writing. Other persons with aphasia have less difficulty speaking and more difficulty understanding what they hear or read (receptive

aphasia). They may misinterpret words, require extra time to process what they hear, or need pictures or gestures to supplement spoken language. In some cases, there may be difficulty with both speaking and understanding (global aphasia).

Aphasia may be mild or severe. For example, mild aphasia may only be apparent in group settings, when rate of communication is increased or when sentences are long or grammatically complex. In addition to aphasia, poor articulation or difficulty in coordinating speech mechanisms may also be observed and speech may be slurred and difficult to understand (dysarthria). Language difficulties can significantly impact communication and social relationships. Family members and friends may need to learn different types of communication strategies—how to simplify sentences, use gestures, allow increased time, provide communication cues or communicating using alternate means such as touch, pictures, gestures, or technological and communication aids. See Table 6.1 for additional management strategies for language problems. A speech-language pathologist can work collaboratively with families and other health care team members to address a person's communication needs.

Changes in emotional control: Sometimes, the area of the brain that controls and regulates emotions is affected by the injury and the person experiences emotional fluctuations. Frequently, the person's emotional reaction does not match the actual situation. For example, the person may laugh when something is not funny or cry inappropriately. Emotions can appear very quickly and intensely, but they often do not last long. It is important to recognize that the person's emotions may not actually match what the person feels. In other words, they may not be able to stop crying even though they are not feeling sad. These sudden changes in emotion can be confusing to others, but it is important to keep in mind that these changes can occur without any apparent reason.

Anger and frustration may also erupt easily and without warning. The person may be extremely irritable with a quick temper. They may yell, shout profanities, throw or bang objects, or threaten to hurt others over insignificant events or when they become frustrated.

Family members can help by remaining calm, and by redirecting the person's attention or taking them to a quiet area so that they can regain emotional control. Sometimes self-calming strategies (such as closing eyes and visualizing a calm ocean) or relaxation techniques can be taught. In some instances, a behavior management program may be required. A psychiatrist or psychologist should be consulted when there are emotional or behavioral issues. Medications may be prescribed by physicians to help stabilize emotions or decrease their intensity.

The Effects of Post-TBI Symptoms on Daily Life

A person living with brain injury is faced with multiple challenges in everyday daily life activities that were previously taken for granted. The person may struggle with morning routines, shopping, managing finances, crossing the street, planning daily schedules, or using everyday technologies. Simple activities may now be effortful,

fatiguing, and overwhelming. While physical symptoms such as weakness, spasticity, or uncoordinated movements pose obvious challenges with navigating one's environment, driving, walking distances, etc., the other symptoms commonly documented post-TBI exert their own impact.

Cognitive deficits post TBI present significant daily life challenges. Difficulties in attending, perceiving, or thinking are not always readily apparent immediately following injury because cognitive perceptual symptoms can be easily misinterpreted. Cognitive perceptual symptoms manifest differently with the demands of the situation or activity at hand. In many situations, the person may function quite well, yet at other times, the person may have difficulty with seemingly simple tasks. For example, a person may have no difficulty keeping track of a conversation with one other person within a quiet home environment; however at a dinner table with 6 other people, the same person may be unable to focus or keep track of what was just said. There may be days that the person has no difficulty getting ready in the morning or shopping and other days when everything falls apart. The degree of distractions, the level of familiarity and predictability, the amount of things that are going on simultaneously, and the degree of structure are examples of external factors that can significantly impact the brain's ability to process, organize, or interpret information. In addition, internal factors such as level of fatigue, anxiety, stress, pain, or depression can also affect cognitive and functional performance.

Linda had her own apartment and was generally independent in routine activities. As she was getting ready for a therapy appointment 1 day, she became distracted after breakfast and began emptying the dishwasher. She lost track of time and then panicked when she realized she only had 20 min to get ready. Her anxiety increased as she quickly washed up, got dressed and flew out of the house. When she was a block away, she realized she forgot to comb her hair. She also realized her pants were unzipped and the buttons on her blouse were mismatched. She also discovered she was wearing two different shoes.

Cognitive lapses such as forgetting to do something, losing track of something that was just done, or doing task steps in the wrong order are more likely to emerge when a person is anxious or stressed. The person may be generally independent in dressing but under some situations, they may be more likely to make errors. Similarly, slight differences in instructions can impact performance.

John was told to make a ham and cheese sandwich for lunch and he had no difficulty. However, when John was asked to see what was available in the kitchen and make himself something for lunch, he became confused and overwhelmed and did not know where to begin.

The latter instruction is less structured and requires the person to initiate ideas, make choices or decisions, and formulate goals. Thus, across all daily life activities, it is important to carefully observe the conditions which seem to enhance or support function as well as the conditions under which cognitive symptoms are most likely to emerge. Slight changes in instructions, environments, and activities can significantly impact performance. See Table 6.1 for additional management strategies for cognitive problems.

There may also be situations in which the information presented to the person with TBI is lost. This may occur due to factors such as the amount of information presented and the way it is presented (i.e., organized versus disorganized). As a result, the person may appear frozen, agitated, or anxious.

Cognitive fatigue is an additional symptom that is highly prevalent post-TBI. Cognitive fatigue is seen when the task requires a greater effort to complete than the person's current cognitive skills. The thinking effort causes a decrease in task performance. It is important to recognize the signs of cognitive fatigue and the warning signs of cognitive overload so that adjustments can be made to increase the functional abilities. See Table 6.1 for additional management strategies for dealing with cognitive fatigue.

Persons with brain injury experience cognitive and perceptual symptoms differently from one another. These symptoms are inter-related and can impact all aspects of everyday function.

Impact of Specific Cognitive and Perceptual Symptoms on Activities of Daily Living

Reduced initiation or "Adynamia": The drive or passion to engage in past activities may be diminished following a brain injury. Loss of spontaneity and drive or apathy may be observed and mistaken for laziness or depression. A disassociation between what one says they will do and what he or she actually does is often observed. The person may verbally state that they would like to take a walk or call friends but then fail to actually carry out their intentions.

Kathy was described as a "go getter" before her injury. In addition to juggling a full time job, she exercised daily, enjoyed swimming all year round at a local pool, participated in a reading club with friends, volunteered at a local charity, and loved to cook and try new recipes. Now, 6 months after her injury, Kathy sits around her house all day long and contentedly watches TV, day after day. She does not initiate or show any interest in exercise, swimming or cooking. Hours will pass and dishes are left in the sink, bills are left unpaid, phone messages are not returned and errands are not done. When her lack of activity and productivity is pointed out, Kathy states that tomorrow she will get to her errands, but day after day is the same. If someone directs Kathy to do activities, she does them, but she doesn't go any further. Kathy does not show signs of depression. She has a good appetite, has no difficulty sleeping and does not express sadness. She has good intentions but she has difficulty translating her intentions into actions and getting herself going.

Difficulties in initiation can range from severe to mild. The person may not initiate routine everyday activities such as getting ready in the morning and preparing meals or snacks. If someone reminds the person to get washed or dressed, he or she typically can complete the task but they do not initiate these activities themselves. In a hospital setting, where others tell you where to go, when and what you should eat, and what to do, the difficulties in initiation can be less apparent. However, the lack of structure within a home environment can significantly increase these symptoms.

In mild cases, the difficulties in initiation may be less obvious but friends and relatives may perceive a drastic change in personality. A person that always had an opinion, and initiated questions, conversations and activities, may appear to be passive, dull, or “blank.” The person may have difficulty generating ideas.

When Kathy was asked about all of the things she could make for dinner she was only able to state two things and then drew a “blank.” When given hints, she could think of additional ideas but she needed someone to prompt her to keep the ideas flowing.

A fixed and structured daily routine can decrease initiation difficulties. In addition, external cues such as index cards with conversation starters or aids such as a vibrating pager or alarm on a cell phone can help someone initiate conversations or actions. A highly structured program that involves structured goal-directed activities, motivational incentives, and monitoring of the number and length of time spent of activities may be beneficial. See Table 6.1 for additional management strategies.

Filtering information/selective attention: Our brain acts as an automatic filter and helps to decide what we should pay attention to and what we should ignore. For example, while sitting in a room listening to a lecture, we are able to tune out the sound of the traffic on the street; we ignore the different decorations on the wall and focus on the lecture. If we tried to take everything in at once, we would not be able to process the lecture. Following a brain injury, the process of filtering out unimportant information may be disrupted. The person may get easily sidetracked by information that is unimportant or irrelevant to the task at hand. It may seem impossible to focus on a task when other things compete for attention. It may also be hard to make decisions or prioritize because everything may seem to have equal value. The person may be easily overwhelmed because they are not sure where to direct their attention.

Janet went to the supermarket but she didn't know where to begin. Everything looked the same. She looked at the shelf with soup cans but she couldn't decide which one to buy. The number of items on the shelf, and the noise, signs, and lights were overwhelming; she left to go home without purchasing any of the items that she needed.

Shopping involves negotiating crowds and busy environments and ignoring products that are not needed. A person with a brain injury may find the experience of shopping completely over-stimulating as they may not know where to focus their attention. They may find themselves wandering aimlessly up and down the aisles without buying anything, or conversely they may find themselves distracted by extraneous information or buying extra things they do not need. Activities such as shopping, going to a mall or restaurant, crossing the street and taking the subway or bus can all become very difficult because of the experience of “overload.”

Processing speed: A person's actions and responses may be exceedingly slow. When processing time is slow, the person requires extra time to understand or comprehend information and to speak or respond. They may miss information during conversations, speak and move slowly and take twice the time to complete daily tasks.

Impulsivity/disinhibition: Difficulties in modulating the speed of response and thinking before acting or saying something is described as impulsivity and/or disinhibition. For example, a person may quickly take clothes out of the closet during dressing, without considering whether the clothes match and are appropriate for the weather or occasion. Crossing the street may be dangerous as the person may dart into the street without thinking or looking for moving vehicles. They may impulsively purchase things that they do not need or fail to consider prices. This can create financial strain and tension between other family members. The tendency to jump into a task quickly without planning ahead or without monitoring actions can result in disorganization as well as errors in judgment and safety. It can also affect the ability to drive, or sustain employment and interpersonal relationships as described later in this chapter.

Getting stuck/alternate attention: A person with brain injury may have difficulty shifting from one activity to the next. As they become involved in one aspect of the task (e.g., making a salad) they may have difficulty moving their focus of concentration to other parts of the activity (monitoring a casserole in the oven). Moderate–severe difficulties are called perseveration and are characterized by repetition of actions that are not related to memory difficulties.

Tim was making tea. He moved a tea bag in and out of the cup repeatedly. He seemed unable to move on to the next step. When he was asked if he was finished with the tea bag he said yes, but continued to move it in and out of the cup. When he was asked to put the tea bag down and put 1 teaspoon of sugar in his cup, he did so but instead of putting 1 spoon of sugar, he put 3 spoonfuls of sugar. Tim had difficulty stopping his actions and tended to repeat himself.

In addition, to repetition of actions, a person may become stuck on a thought or past event. They may have difficulty “letting go” of insignificant events and bring up the same topic or issue again and again. This can be described as a “stickiness of thinking” or cognitive inflexibility.

Mary was upset that her physician told her she could not drive for the next 6 months as she felt she was ready to resume driving. She brought up the issue of driving multiple times in every conversation she had, regardless of with whom she was speaking.

In addition, situations may be perceived from only one perspective and the person may have difficulty seeing other viewpoints or generating alternatives.

Processing visual perceptual information: Visual perceptual changes can result in difficulties in processing, understanding, or interpreting visual information. Although vision may be normal, the person may overfocus on some parts of visual information, while missing other parts. There may be misidentifications, omissions, and a failure to locate, align, or position objects accurately. Reading may be characterized by a tendency to skip over letters or words or misread letters.

Containers or objects that are similar in size and shape may become easily confused as key visual details may be missed. For example, a person may misidentify a tube of hand cream as a tube of toothpaste and put the hand cream on their

toothbrush. It may seem as though the person is disoriented and confused, however memory and attention may be intact. The brain may be unable to accurately process visual and spatial information in the world around them.

Spatial difficulties may result in improper alignment and positioning. For example, a person may put on a shirt backwards or inside out. They may put their hand through the wrong end of a sleeve or miss or misalign buttons without realizing it. Simple tasks such as fitting a plug in an outlet, opening a combination lock or putting batteries in a flashlight may seem impossible.

In some cases, the person may have difficulty attending to both sides of space. Attention may be over-focused on the right side of the environment and the person may miss information on the left side. This is sometimes described as left or right neglect or inattention (depending on the side of space that is ignored). Crossing the street or driving will be unsafe if the person has difficulty simultaneously attending to all aspects of the environment.

Visual perceptual difficulties can result in difficulty locating, distinguishing, and identifying needed items on shelves or cabinets. Tasks such as pouring, estimating quantities, measuring or dividing amounts, and arranging food on trays, platters, or within confined spaces may be challenging. Setting a table may be particularly difficult as it requires the ability to estimate space, and align or position items in relation to each other. Other aspects of cognition contribute to such limitations as well. Visual perceptual difficulties can also make it difficult to perform work tasks such as accurately entering or reading information on spreadsheets or space and align information accurately on a page during math or writing.

Language abilities: Language comprehension and expression are often impacted by TBI, as discussed in the previous section.

Loosing track during activities/working memory: The ability to keep track of what you just said, read, or did is referred to as working memory. Working memory is commonly affected after a TBI. The inability to hold all parts of an activity or situation in mind as one is performing an activity can result in continual errors in daily tasks. For example, a person may end up washing their face twice, because they lost track of steps they previously completed. They may forget how many pills they just swallowed while taking medications or during cooking, may forget an item they just placed in the oven. Decreased working memory can narrow the attentional lens and reduce the ability to multitask.

Jane previously loved to cook and entertain but she found that cooking a simple meal took her twice as long as it did before because she could only handle one thing at a time. "I make a salad first and then I heat up sauce and then I boil water for pasta. Before I did it all at the same time but now it is too confusing and I always end up forgetting something, so I just do it one at a time."

Working memory is considered to be a foundation for higher cognitive processes. If a person is unable to keep track of all parts of a situation, it influences the ability to make sound decisions, organize information, and solve problems.

Remembering information over time/episodic memory: After a TBI, remote or long-term memory for events that occurred years prior to the injury is commonly unaffected, however new learning or the ability to remember from day to day, since the injury, is frequently decreased. The person may recall details of vacations taken years before the injury but at the same time they may completely forget a conversation or event that occurred the day before. Activities that involve active “doing” and are highly meaningful or have emotional value may be more likely to be remembered than conversations or facts.

The process of memory can be described as the three R’s (registration, retention, and retrieval). Registration involves taking in all aspects of a situation and is related to attention and working memory. Retention involves storing or holding onto information over time (retaining) and retrieval includes pulling the information out of memory when it is needed. Other cognitive processes such as attention, the ability to filter distractions, and initiation influence memory processes. If a person does not fully attend to information that is presented, it is unlikely that they will be able to recall the information at a later point. Similarly, the process of retrieval or trying to recall where you left something involves searching your memory by initiating asking yourself questions. A person with difficulty in initiation may not be able to generate the systematic search of their memory.

Memory problems can be related to difficulty taking information in, storing it, retrieving it, or a combination of all three.

A therapist showed Jeff how to operate a new microwave oven that was just installed in his home kitchen. Memory for this activity can be affected in different ways. (1) Jeff was unable to attend or keep track of the directions during the activity (working memory) and therefore does not recall the instructions at a later time. (2) Jeff paid careful attention to the instructions, but the next day, he had little to no recollection of the activity that took place. In other words, Jeff was able to take in or register information but was unable to hold or store the information over time. (3) Jeff was unable to recall the activity but when he was reminded of the learning context, location and other key information, he was able to recall more details. This suggests that Jeff stored the information but was unable to search or locate it in his memory. (4) Jeff had no recollection of learning how to operate the microwave oven but when he saw the microwave oven, he automatically knew how to operate it. This type of memory is called procedural memory or the unconscious memory of how to do something. (5) Jeff recalls how to operate the microwave but he forgot that he was supposed to put something in the microwave at 3:00 p.m. Memory for future intentions is called prospective memory.

Memory provides continuity from day to day and helps us learn from our experiences. Memory difficulties impact learning and all facets of daily life, thus it is important to understand the person’s memory strengths and limitations when planning treatment. Different types of memory problems require different treatment strategies. In some cases, external aids such as a voice recorder, smart phone, notebook, or pocket personal computer that can store or hold information over time may be recommended. Persons who are comfortable with technology or used such devices prior to their injury may more easily accept using them to support their memory. External aids also require ability to anticipate and recognize problems. In other situations, the focus of intervention may be on helping a person use strategies

to more fully attend to and deeply process or take in information. Errorless learning, which capitalizes on procedural memory and is typically unaffected in persons with TBI could be used when learning new tasks through repetitive practice. Learning without errors may be used to enhance the ability to learn a specific task or routine. See Table 6.1 for additional management strategies for memory problems.

Organizing, planning, and problem solving/executive functions: The cognitive symptoms described above can reduce the ability to plan, organize, and solve problems. Inability to keep track of all aspects of a situation or activity, restrain impulses, self-monitor performance and plan or think things through before acting can result in a haphazard approach to problems and situations. As a person becomes involved in an activity, the main goal may fade away, and the person may become sidetracked or never complete what they set out to do. Problem solving may be reduced as the person is unable to consider all the variables of the problem simultaneously, anticipate consequences, recognize or choose the most important aspects and make decisions that follow a logical sequence.

Organization of time, materials, and/or thoughts is challenging. As one brain injury survivor stated . . . “*it feels like a bomb exploded in my head and all the pieces are floating around my brain but I can’t connect the pieces.*” The person may jump into activities without gathering the necessary materials.

Robert was making coffee for breakfast and realized he needed milk. He went to the store to get the milk but when he came home he also realized he did not have sugar and went back to the store. By the time he was finished breakfast, it was almost lunchtime. Robert failed to plan ahead and anticipate the materials that were needed. As a result, the simple task of making breakfast became time and energy consuming.

Persons with brain injury often have difficulty keeping track of materials and time as they are doing an activity. For example, they may spend extra effort looking for materials that were misplaced, repeat steps that were already completed, or fail to consolidate steps and materials, resulting in inefficiencies or a disorganized quality of performance. Similarly, conversations or written communications may be characterized by a tendency to jump from one idea to another. The person may have difficulty expressing their thoughts in an organized way.

The cognitive perceptual symptoms described above can impact the same everyday activities in different ways. For example, managing finances requires the ability to make good judgments regarding purchases, compare and contrast prices, keep track of spending, plan and stay within a budget, use an ATM machine, organize and remember to pay bills, discriminate numbers, calculate and make change. Brain injury survivors may have difficulty with the task of managing finances for very different reasons, depending on the underlying cognitive perceptual problem.

Kay realized that she paid the same bill to a company 3 times but she neglected to pay 2 other bills and received overdue notices. In contrast, Jon paid all of his bills on time, however, he made frequent careless errors such as writing out the wrong amounts on checks and often purchased items he did not need while Monica had difficulty quickly discriminating coins and bills and selecting the right amount of money to pay for items in the store.

A clinician can assist in analyzing the reasons why a person is having difficulty in a particular daily life activity as well as to provide methods to enhance everyday function. Careful manipulations or modifications of the environment and activity as well as training strategies within the context of everyday activities to help brain injury survivors learn to recognize, monitor, and compensate for cognitive symptoms is an important part of rehabilitation programs. See Table 6.1 for additional management strategies for cognitive behavioral problems.

Awareness/insight into physical and cognitive changes: One of the obstacles to rehabilitation after brain injury is diminished awareness of difficulties. After a TBI, the person may not be fully aware of physical impairments, limitations in activities, or changes in thinking skills, emotional control, and behaviors. This may be related to the brain injury and associated cognitive deficits, the person's psychological response or a combination of both. It takes time to recognize and accept the changes that have occurred. A person may not make the connection between the injury and changes in performance. They may not recognize or understand the changes that have occurred in themselves. Awareness often emerges slowly with time. After a brain injury, the way the brain processes information is different. The same methods that the person used before the injury may no longer work.

Jane never had to write things down. She was proud of her organized approach to tasks and situations and ability to always be able to keep track of everything she needed. After a mild brain injury, Jane found herself constantly losing things, and forgetting things she had just done. Her apartment was completely disorganized with piles of clothes and papers. She felt like she was losing her mind. She knew something was different but she blamed it on her fatigue and lack of energy and did not acknowledge any changes in thinking skills.

Jane was approaching activities the way she did before the injury, without writing things down, or creating a list. Jane needs to learn about her new strengths and weaknesses and explore different methods or strategies that she may not have needed to use before the injury. See Table 6.1 for suggested strategies addressing self-monitoring and awareness problems.

Denial or a psychological response to an injury or illness is different than impaired self-awareness as a result of brain injury (Kortte & Wegener, 2004). Denial is a coping strategy or a defensive reaction that is associated with personality characteristics such as a history of denying inadequacies or a need to be in control. Denial can be adaptive in the early stages of an injury, however if it persists, it can prevent a person from developing realistic goals and plans. The person may have at least partial awareness of mistakes but denies problems, over-rationalizes mistakes, makes excuses, or places blame for difficulties on external sources such as the task itself or other people.

Impaired self-awareness as a result of brain injury is a lack of information or an inability to perceive the impairments (Stuss, Picton, & Alexander, 2001). The person does not recognize the changes that have occurred. In severe cases, the person may not acknowledge physical changes resulting from the injury and attempt to do tasks such as getting out of bed without assistance despite an inability to move one side of their

body or having casts on their legs. More typically, the person acknowledges physical limitations but does not recognize the less obvious cognitive and behavioral changes.

Often both denial and impaired awareness as a result of the brain injury interact together and are difficult to separate, such as in the example of Jane above. As the person begins to recognize changes that they do not understand, they may cope by denying that anything is wrong. Decreases in awareness therefore can be a combination of partial recognition of limitations and defense coping mechanisms. Reactions of blame, anger, or hostility to feedback tend to be more related to denial mechanisms, whereas reactions of perplexity or indifference tend to be related to impaired awareness resulting from neurological deficits (Prigatano, 2008).

Regardless of whether impaired self-awareness is related to neurological or psychological defense mechanisms, an inability to recognize, acknowledge, or accept difficulties can result in overestimation of abilities and prevent a person from developing adaptive strategies to manage cognitive symptoms, compensate for limitations, and safely perform functional tasks. Overestimation of one's abilities also creates repeated experiences of unexpected failures that can impact a person's sense of control over performance.

For example, one survivor said *"I never know when lightning is going to strike. Sometimes everything turns out well but other times everything seems to go wrong."* Decreased ability to accurately anticipate outcomes of everyday activities can cause a person to believe that their own performance is outside of their control or unpredictable. Decreased or partial awareness can lead to perceived loss of control, anxiety, decreased self-confidence and self-esteem as well as frustration, anger and depression as the person gradually experiences difficulties with activities they took for granted before the injury.

Very often, as awareness begins to emerge and the person recognizes that they are having difficulty, there can be accompanying feelings of loss of a sense of self. For example, one survivor said *"I think differently and I can't do the things that I did before...My memory is unreliable and my brain doesn't always take everything in. I feel different, but I look the same. Everyone expects me to do the things that I did before but I can't. I don't know who I am anymore. I say things without thinking and I made embarrassing mistakes. My brain is messed up."*

In this case, the person is aware of their cognitive symptoms and changes in thinking but at the same time, the person perceives a lack of control over these symptoms and is experiencing a "shaken" sense of self or loss of self-identity.

Cognitive skills are frequently associated with a person's self-identity. For example, a person may be described by others as "detail oriented" or "well organized." When a person's brain no longer processes information the way it did before the injury and a person is unable to return to their former lifestyle, there is a sense of loss. The person has to rediscover their strengths and weaknesses as well as to rebuild their sense of self-identity. An important step in the recovery process is recognizing, understanding, acknowledging, or accepting difficulties so that the person can regain a sense of self-identity, perceived control, and competence over performance.

Participation

The myriad of symptoms following TBI often result in limitation in an individual's ability to participate fully in society. Physical symptoms (gait disturbance, slowness, weakness), cognitive symptoms (slowed processing speed), and psychological symptoms (depression) often preclude an individual from community re-integration. Additionally, the environment may be enabling or disabling. For example, ramps will facilitate entry of an individual with weakness into a local support group. A work environment with fewer distractions may facilitate employment.

The ultimate goal of rehabilitation following a TBI is helping a person re-integrate back into the community and his/her life. This includes independent living or competence in everyday tasks, social participation, and the ability to develop or maintain social relationships, resumption of productive, and meaningful activity such as employment, return to school, community activities, and leisure pursuits. Outcome studies indicate that between 26 and 45% of people with severe TBI are poorly integrated into their community in the longer term (Temkin, Corrigan, Dikmen, & Machamer, 2009).

The Impact of TBI on Personality and Social-Emotional Functioning

Psychosocial functioning: Feelings of sadness, anger, and frustration are normal responses to the losses and changes a person faces after a TBI. It takes time and support to adjust and adapt to the changes that have occurred. High levels of anxiety and loss of self-esteem can also occur as a person experiences repeated and unexpected failures. If these feelings interfere with recovery or everyday functioning, treatment from a psychologist or psychiatrist is required.

Persons with TBI have a higher risk for depression than persons in the general population (Whelan-Goodinson, Ponsford, Schonberger, & Johnston, 2009). Depressed mood in persons with TBI is associated with irritability, frustration, anger, hostility, rumination, negative thinking, poor appetite, and sleep disorders. It is often difficult to diagnose major depression or other psychiatric disorders due to the cognitive, behavioral, and emotional symptoms that occur with brain injuries as these symptoms overlap with psychiatric disorders (Ciurli, Formisano, Bivona, Cantagallo, & Angelelli, 2010). Persons with TBI and depression or anxiety tend to considerably underestimate their abilities and self-report more cognitive and physical impairments than observed on testing. This is different than persons who exhibit unawareness and tend to overestimate abilities (Seel, Macciocchi, & Kreutzer, 2010).

Coping skills are significantly compromised after a TBI, resulting in increased vulnerability to the effects of stress, depression, and anxiety. Coping involves the ability to identify problems, generate alternate solutions or possibilities, and view a situation from different perspective; however, these skills may be directly affected by the injury. Life events such as a move to a new apartment, tensions in relationships or a death of a close relative or friend can create stress that is overwhelming.

A person that was functioning well can begin to slip backwards. Everyday function can quickly deteriorate under pressure and stress. The reduced coping abilities following a brain injury make it important to have long-term psychological supports in place to help a person deal with life challenges when needed.

Social participation: Social isolation is one of the main issues affecting life satisfaction.

The cognitive symptoms observed following a brain injury, significantly impact one's personality and social and interpersonal relationships. Social situations require the ability to simultaneously attend to the overall context of a situation and pick up on subtle nonverbal or emotional cues in facial expression or body language, as well as keep track of and understand the content of conversations. Many cognitive skills including the ability to infer what another person might be thinking or feeling, "reading between the lines," recognizing the intentions of others and hidden agendas, viewing a situation flexibly from different perspectives and anticipating consequences are involved in interpersonal situations. A person may fail to pick up on social cues and say things that are inappropriate to the context or situation. Slow processing speed can result in challenges in keeping up with the pace of a conversation, causing a person to withdraw. Difficulty in organizing one's thoughts may result in a tendency to jump from one idea or thought to the next. The person may stand out as "odd" because they may repeat things that were previously said, become sidetracked or say something that is inconsistent or inappropriate to the topic. Disinhibition or difficulty monitoring oneself can result in behavior that can be interpreted as rude, inappropriate or offensive. A person that was previously reserved or shy may suddenly shout things out in public, make inappropriate sexual advances, comments, or use profanities. They may raise their voice or speak in a threatening tone without realizing it and may say whatever is on their mind without thinking ahead of the consequences.

At the opposite end of the spectrum, a person that displays decreased initiation may have difficulty sustaining engagement in meaningful conversation. A person who was previously outgoing, and friendly may sit passively, without asking others questions or without the ability to generate ideas for questions or conversation. They may show little emotions and appear bored or disinterested in others.

Problems in cognitive flexibility or the ability to view situations from different perspectives can also be problematic. The persons may appear self-centered and less empathetic because they have difficulty understanding the other person's views or putting themselves in another person's shoes. A person may not see anything wrong with coming into a room and interrupting a serious conversation or changing the TV channel when others are in the midst of watching a movie because they may be overfocused on their own goals and be unable to see a situation from the perspective of others.

Persons with physical problems resulting from the injury may also face challenges and barriers to their participation. Restrictions in the person's physical ability to leave the home and/or enter into public spaces may prohibit the ability to be economically and socially engaged in the community. If the person is not able to drive a personal vehicle, alternative community mobility options may not be available or accessible to support community social participation.

All of these problems can decrease the ability to form new friendships or relationships as well as contribute to a breakdown of existing social relationships. The changes in social participation can be subtle. Gradually friends detect personality or cognitive changes but may not fully understand or know how to deal with these changes. They may not know what to say when the brain injury survivor cannot find the right words, drops a glass due to incoordination, repeats the same story three times or when he or she has an emotional outburst over an insignificant incident. Observed changes may be misinterpreted as laziness, lack of interest, resistance, irresponsible, unreliable, or moody. Friends may question whether the person is going “crazy.” Over time, former friends gradually fade away or become fewer in number. Inability to form or sustain friendships and meaningful relationships over time is a frequent problem following TBI.

Cognitive limitations make it difficult to create new social networks. Comprehensive rehabilitation programs incorporate training in social communication and social skills within treatment. Social training may involve role playing or watching video scenarios of social problem situations and discussing alternative responses. It also may include group activities that require negotiation, compromise, and team work. Activities that involve working together for a common cause, such as producing a newsletter, designing a web page, creating fund raising activities such as bake sales, raffles, or craft fairs can be used to simulate the interpersonal skills required for collaboration in the workplace. Recently, an International Brain Injury Clubhouse model has been established in locations in the United States and Canada. The Clubhouse is a community of members (brain injury survivors, health professionals, and families) that encourages community re-entry and offers vocational and social support systems (International Brain Injury Clubhouse Alliance, 2016, www.braininjuryclubhouses.net/clubhouse.aspx). It provides long-term services to TBI persons living in the community.

Changes in family dynamics: A TBI can have a dramatic impact on the entire family. The focus of rehabilitation and recovery typically centers on the survivor but the injury can also have a negative impact on family members as well. Their lives, plans, and goals for the future have all been affected. Family members may feel frightened, anxious, and concerned about the cognitive and behavioral changes they are observing. All of the cognitive, emotional, and psychological changes described above can disturb and strain the existing family relationships. Even subtle cognitive difficulties can strain relationships. Changes in intimacy often occur and the person either fails to initiate or show interest in intimacy or may demonstrate inappropriate or aggressive sexual behaviors.

The cognitive and behavioral changes that can occur after an injury are a main source of stress and strain in relationships. It is not uncommon to feel that the person is no longer the same. A study that examined family members' reactions to neurological injuries found that one-third reported being “married to a stranger” and nearly half reported feeling trapped and not having a spouse (Mauss-Clum & Ryan, 1981). Family members may have mixed or ambivalent feelings about the person with the injury. They are happy that the person survived, but at the same time may

have negative feelings about the changes in the person's behavior and personality. Other friends and relatives who do not live with the person, may not readily see or understand the changes that have occurred. This can make it more difficult for those that are closest to the person with the injury, as it can create additional feelings of isolation, loneliness, resentment, and guilt. The process of dealing with the loss of a person they once knew, and adjusting to the new changes in that person requires time, support, and family counseling. It is not uncommon for many marriages to end in separation or divorce.

In addition to the challenges of adapting to personality changes, there are changes in roles and responsibilities that create further stresses on family members. Spouses or close family members may feel completely overwhelmed by loss of income, financial pressures, and the burden of extra responsibilities. It is not uncommon for family members to neglect their own personal needs and health or put their own goals and careers on hold, while focusing on the survivor. All of this increases vulnerability of family members to depression, anxiety, social isolation, and caregiver burn out. Family members have an essential role in providing support during recovery. Their ability to provide appropriate structure to enhance functioning is critical to the brain injury survivor's success; however, if family members are completely overwhelmed, it reduces their ability to support the person with the injury. It is essential for families to collaborate with rehabilitation professionals across all phases of recovery. Families need assistance and help in learning how to adapt to the changes with the individual (see Table 6.1 for sample strategies the family can use). They need long-term support to deal with their losses and to take care of themselves as well. Research indicates that a combination of family education, psychological support, family counseling, and skills training can benefit families (Kreutzer, Marwitz, Godwin, & Arango-Lasprilla, 2010). The Brain Injury Association of America (BIAA) and its State chapters are important resources that provide information, education, and support to persons with brain injury survivors and their families.

Driving: Driving requires the ability to scan and attend to all aspects of the environment, follow traffic rules, anticipate problems, and react quickly to unpredictable situations. Problems in concentration, restraining impulses and actions, or simultaneous attention to all aspects of the environment can interfere with the skills needed for safe driving. A person with a brain injury should be assessed for ability to return to driving by a professional who is knowledgeable in cognitive disabilities and their effect on driving. Occupational therapists typically perform both clinical and on-road assessments of driving performance. Inability to return to driving may increase dependence on others and reduce social and community participation. The person may need assistance and mobility training in learning to use public transportation independently.

Employment issues: One of the most common long-term consequences of a TBI is difficulty with or inability to return to work. Estimates of long-term return to work after TBI vary depending on the severity of the injury, cognitive functioning, the person's age and pre-employment status. One study found that less than half of persons with brain injury are able to maintain stable, uninterrupted work over time, after a TBI (O'Neil-Pirozzi, Corrigan, & Hammond, n.d.).

Work is a key issue as being employed has been associated with better life satisfaction and social re-integration of persons with TBI. Even persons with a mild TBI can experience significant cognitive problems that interfere with the ability to sustain competitive employment over time or earn pre-injury salaries. The recent American Community Survey (ACS; Gamboa, Holland, Tierney, & Gibson, 2006) found that when persons with mild TBI are able to return to work competitively, they are more likely to earn less than those without a disability. The economic impact on the individual and society is enormous. The loss of productivity and wages, together with costs associated with management of TBI, has been estimated to be 22 billion annually (Fadyl & McPherson, 2009).

Following a mild TBI, persons can also experience a number of symptoms that affect their capacity to work. Short-term memory difficulties can make it hard to learn new material. Problems in filtering can reduce the ability to stay focused on a task or goal and set priorities. Fatigue or other physical symptoms may result in limited energy or stamina. Language, visual, or emotional changes can further compound difficulties. It is important to have guidance and advice from health professionals as to when to return to work, as returning to work too soon can be detrimental.

Jody returned to work part time as a caseworker after a mild TBI. On the first day she felt dazed and “out of it.” She had difficulty concentrating and was easily distracted by phones ringing and the nearby conversations of others. Her supervisor found her a quiet office space but Jody continued to struggle with difficulties in focusing. She was putting in extra effort and energy to complete only half of the work she did before and by early afternoon she found herself mentally exhausted and fatigued. She also experienced difficulty setting priorities, organizing her work and ensuring that her work was complete. “It seemed that everyone was working and speaking at lightning speed and I could not keep up.” Although co-workers were initially sympathetic, some questioned her disability as they could not see that anything was wrong. During social conversations, she heard others quietly giggling and realized she had repeated the same sentence. She found herself increasingly isolated and withdrawn. Her self-confidence and self-esteem rapidly deteriorated and she could not understand why she couldn’t function like she did before. On one occasion she was speaking to a client over the phone, and began raising her voice without realizing it. Her employer asked to take an extended medical leave.

Jody’s case highlights the persisting and hidden symptoms that can occur after mild TBI, as well as the challenges that a person who returns to work may face. Co-workers may easily misinterpret errors or cognitive symptoms as laziness, lack of effort, or not caring. This can create resentment and tensions with co-workers. Accommodations such as a reduced work day and schedule, additional time to complete tasks, or additional structure (written directions) may be needed. If a person returns to work too soon and experiences failure, such as in the case with Jody, secondary problems such as anxiety and depression can occur and further compound the recovery process. A person with a mild TBI may find that as they re-enter the work force, they need to accept a position with lower salary and responsibility because they are no longer able to handle previous responsibilities.

Persons with moderate to severe problems may need intensive support and a specialized vocational program to return to work. Specialized programs typically include simulation and practice of work skills as well as guided practice in actual work situations. Such programs typically have access to special job placements and some programs use a supported employment model that includes use of job coaches. Job coaching includes one to one training within the work environment. In general, successful return to work after a TBI has been shown to improve with specialized vocational interventions (Fadyl & McPherson, 2009).

Return to school: The problems in returning to school to resume previous studies or to pursue future goals parallels that of returning to employment. Students may need additional resources, support, and accommodations to be successful including extended time for assignments and exams, use of a reader, reduction of course load, a note taker, tape recording of lectures, and structured directions for assignments. Even with accommodations, many students need to modify their course of study or revise vocational goals.

Leisure: Following a TBI, it is important for a person to find meaningful activities that bring enjoyment and satisfaction. When we immerse ourselves in hobbies such as gardening, photography, pottery or something else that we love doing, it stimulates our minds, structures our time, connects us with others, and helps us feel good about ourselves. Part of the process of rebuilding a sense of self is helping a person connect to those activities that bring pleasure, as well as a sense of accomplishment and fulfillment. Sometimes, this involves re-connecting with previous interests and activities and other times, it may involve discovering new activities to replace or substitute for activities in which the person is no longer able to engage. If a person is unable to return to work, leisure activities and interests become a main source of life satisfaction. Engagement in such activities is important to one's sense of accomplishment, self-esteem, self-confidence, and overall health (Bier, Dutil, & Couture, 2009).

Cultural Considerations

Defining independence, community participation or quality of life can differ depending on the person's cultural values, beliefs, and socioeconomic status as well as the environment in which they live (Sander, Clark, & Pappadis, 2010). Health professionals sometimes assume that everyone values independence in daily activities. Some family members may want to help the person with brain injury with routine activities because they believe that it is their duty to take care of him/her. Other activities such as participating in religious activities, working, or socializing with others may be more important to the person or their families than independence in routine activities such as dressing. Some cultures and communities place more importance on families or social networks, while others place more importance on work or engagement in competitive sports (Arango-Lasprilla & Kreutzer, 2010). Individuals with brain injury and their families are encouraged to collaborate closely with health professionals by sharing their values and identifying the goals that are meaningful and important to them.

Factors That Affect Recovery and Length of Recovery Time

Although the most rapid changes occur within the first 6 months after an injury, it has been shown that even 10 years after an injury, functional changes are still possible (Parish & Oddy, 2007). Factors that affect recovery include age, level of severity of the injury, cognitive functioning, social and family supports, and previous education and experiences.

Rehabilitation is often provided in the early phase of recovery but long-term supports are needed. Living with a brain injury is similar to living with a chronic illness. The person's needs and challenges in daily life will change across time as life circumstances naturally evolve and change. Periodic intense rehabilitation interventions may be successful at many different points across the person's life. An individual with brain injury and his/her family needs long-term resources and supports to maintain and maximize participation in the community and society.

Collaborating with health care professionals and networking through local chapters of the Brain Injury Association or Brain Injury Alliance can help the person with TBI and his/her family return to or create a new life that is satisfying and meaningful.

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