

Traumatic Brain Injury, Level 1

Capable Caregiving for Brain Injury



Aging and Long-Term Support Administration

This curriculum was developed from feedback and input gathered from stakeholders across the state. Primary stakeholder groups included facility owners/providers, managers, supervisors, caregivers, trainers, families, clients/residents, DSHS staff, long-term care ombudsman and advocacy group representatives.

Curriculum Development

Angela Regensburg, MAED

Program Manager, Training Unit Specialty Curriculum & Quality Assurance
Aging and Long-Term Support Administration
Department of Social and Health Services

Contributing Subject Matter Experts

Betsy Jansen

Resource Support and Development
Program Manager
Home and Community Services / AL TSA

Dan Overton MC, LMHC, MHP, CBIS

Traumatic Brain Injury Program Specialist IV
WA Department of Veterans Affairs

David Minor

TBI Council and Fund Coordinator
Home and Community Services / AL TSA

Deborah Crawley

Executive Director
Brain Injury Alliance of Washington | BIAWA
Pooled Alliance Community Trusts | PACT

Jeff Hartson

TBI Survivor and Support Group Coach
Brain Energy Support Team

Marisa Osorio, DO

Assistant Professor
Attending Physician
University of Washington / Seattle Children's Hospital

Nicole Chamblee, CBIS, CIRS-A/D

Resource Center Operations Manager
Brain Injury Alliance of Washington

Scott Bloom

Program Manager
Traumatic Brain Injury Council
Home and Community Services / AL TSA

Curriculum Review and Pilot Testing

Brian D. Cammack, U.S. Army, Retired Critical Care Flight Medic

Tabitha Dominguez, Former Army Medic, TCCC Trainer

Gloria Kraegel, Executive Director, Brain Energy Support Team

Robert McHaney, MPH, NREMT-Paramedic

Nicholas Mehrnoosh, MS, Eastern Washington University

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Module 1: Anatomy of the Brain and Brain Injury Basics

The caregiver will identify parts of the brain and have a better understanding of how injuries may affect a Traumatic Brain Injury survivor. The caregiver will also identify possible signs, symptoms, severity levels, types of brain injury and describe the regions of the brain and functions associated with each region.

Module 1: Anatomy of the Brain and Brain Injury Basics

Objective

The caregiver will identify parts of the brain and have a better understanding of how injuries may affect a Traumatic Brain Injury survivor. The caregiver will also identify possible signs, symptoms, severity levels, types of brain injury and describe the regions of the brain and functions associated with each region.

Overview

We depend on our brain for a large part of our daily function and an injury to the brain can alter our abilities for the short term and long term. Injuries can affect any age group, culture and race in any geographical region, without warning. Brain injury planning, coordination and service delivery must address broad needs across the life span. Every year, millions of people in the United States suffer brain injuries. In Washington state, it is estimated that at least 30,000 individuals experience a brain injury each year. Conservative estimates indicate that 145,000 people in Washington state live with a long-term disability as a result of brain injury. (2019, Centers for Disease Control and Prevention)

Not all blows or jolts result in brain injury. A brain injury can range in severity from mild to severe.

Do you know or care for someone with a brain injury? Imagine if someone close to you had a brain injury – how would you want him or her cared for?

Anatomy of the Brain

Brain Parts and Functions

When the brain is injured, it may be injured in one or more areas. Injury to the brain in various areas and to various degrees contributes to each individual case of TBI being unique. Becoming more familiar with the parts of the brain helps you to better understand potential problems that may result from the injury and possible therapies to promote an improved quality of life for each individual with a TBI.

Frontal Lobe

The frontal lobe is located behind the forehead. This part of the brain is used for executive functioning such as planning, organizing, problem solving, decision-making, memory, attention, controlling behavior, emotions and impulses.

The left side of the frontal lobe controls speech and language. The right side of the frontal lobe plays a role in non-verbal abilities.

Problems that may result from damage to the frontal lobe involve the ability to manage and/or recognize emotions and impulsive actions/decisions (poor judgement), struggles with language, memory, as well as inappropriate social and sexual behaviors.

Parietal Lobe

The parietal lobe is located behind the frontal lobe. The parietal lobe integrates sensory information from various parts of the body. It controls sensations such as touch, hot, cold and pain. This lobe tells us which way is up. It also helps keep us from bumping into things as we walk.

PARIETAL LOBE

OCCIPITAL LOBE

CEREBELLUM

FRONTAL LOBE

TEMPORAL LOBE

BRAIN STEM



Things you might see that may result from damage to the parietal lobe may involve inability to locate parts of the body or inability to recognize parts of the body.

Temporal Lobe

The temporal lobe is located on the sides of the brain under the parietal lobes and behind the frontal lobe. This part of the brain recognizes and processes sound, understanding, producing speech and other aspects of memory.

Things you might see that may result from damage to the temporal lobe may involve hearing loss, language problems and sensory problems such as inability to recognize familiar faces.

Occipital Lobe

The occipital lobe is located at the lower back of the head. This part of the brain receives and processes visual information and contains areas that help to perceive shape and color.

Things you might see that may result from damage to the occipital lobe involve visual problems and distorted perceptions of size, color and shape.

Cerebellum

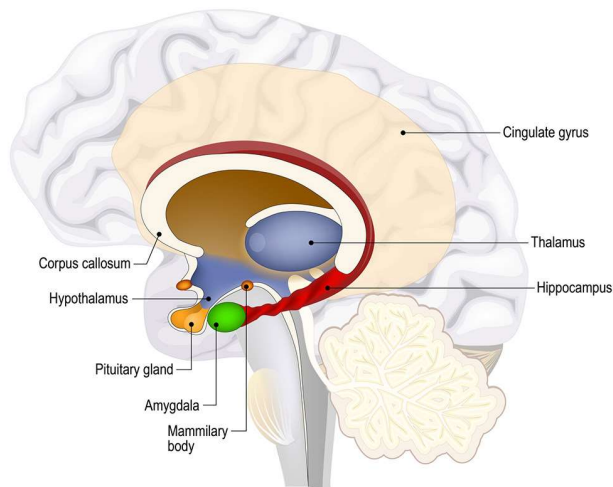
The cerebellum is located at the back of the brain. It controls balance, movement and coordination. The cerebellum allows us to stand upright, keep our balance and move around.

Things you might see that may result from damage to the cerebellum include uncoordinated movement, loss of muscle tone and unsteady gait.

Brain Stem

The brain stem is located at the base of the brain. This part of the brain regulates involuntary functions for survival such as breathing, heart rate, blood pressure and swallowing.

Limbic System



Things you might see that may result from damage to the brain stem could include rapid heart rate, breathing and swallowing.

Hypothalamus

The hypothalamus is located below the thalamus and above the brain stem. This part of the brain helps us to regulate body temperature and recognize when we are hungry or thirsty. It also helps us to identify what mood we feel by releasing and controlling hormones we need to function.

Things you might see that may result from damage to the hypothalamus include issues with sex drive, sleep, hunger, thirst and emotions.

Pituitary Gland

The pituitary gland is located at the base of the brain. It regulates and releases important hormones to our body. The gland plays a big part in our overall well-being. Things you might see that may result from damage to the pituitary gland include high or low blood pressure, fatigue, depression, changes in sex drive, body temperature and pain.

Amygdala

The amygdala is an almond shaped mass of cells located near the hippocampus in the frontal portion of the temporal lobes. The function of the amygdala is formation and storage of information related to emotional events. It is involved in many of our emotions and motivations. It also helps to recognize when there is danger or fear of something.

Things you might see that may result from damage to the amygdala might include memory formation, emotional sensitivity, learning and retention, depression and anxiety.

Hippocampus

The hippocampus is located in the temporal lobe. The hippocampus is hypersensitive to oxygen loss or lower blood flow levels through the arteries, vessels and capillaries. It is responsible for memory creation and retention. It helps us to create new memories and helps us orient ourselves in surroundings.

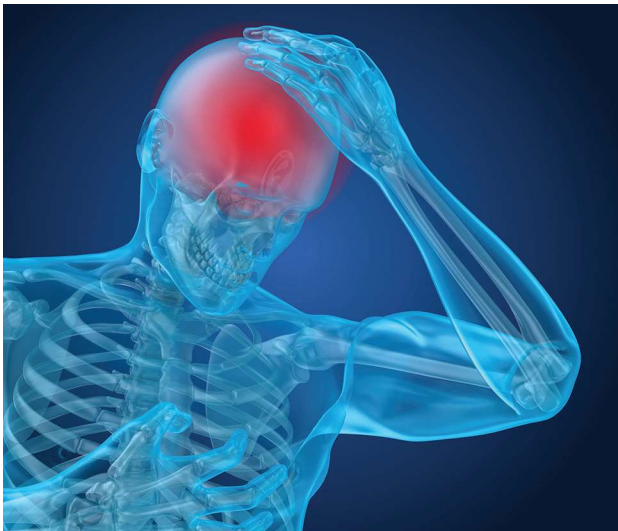
Things you might see that may result from damage to the hippocampus include trouble with new memory creation, new memory retention, mood, confusion and disorientation.

Select a part of the brain listed in this section and discuss what characteristics might be present in someone who has a brain injury affecting this part of the brain.

Types of Brain Injury

Acquired Brain Injury (ABI)

Acquired Brain Injury (ABI) is defined by the World Health Organization as damage to the brain, which occurs after birth and is not related to a congenital or degenerative disease. **Congenital** is a disease or physical abnormality present from birth. **Degenerative** is a disease or symptom characterized by progressive, often irreversible deterioration and loss of function in the organs and tissues.



ABI damages may be temporary or permanent and cause partial or long-term disability or failure to cope with the demands of daily living.

ABI's include TBI's, but may be caused by stroke, lack of oxygen to the brain during near-drowning or suffocation, tumors, drug overdose, anaphylactic shock, an infection in the brain or other causes.

The terms ABI and TBI are not used for a person who has brain damage before birth or whose brain is injured during birth.

Stroke

Strokes are medical conditions in which poor blood flow to the brain results in cell death. There are two types of stroke.

1. Ischemic Stroke is a result of lack of blood flow to the brain.
2. Hemorrhagic Stroke is a result of bleeding directly into the brain or into the space between the brain membranes.

Anoxic

Anoxic brain injury is a serious, life-threatening injury. Anoxic means a total lack of oxygen. The brain requires a continuous supply of oxygen to function normally. Brain cells will start to die within a few minutes if deprived of oxygen.

There are four types of anoxia and each can cause serious damage to the brain.

Anemic anoxia results from blood that cannot carry sufficient oxygen to the brain. Some forms of lung disease can lead to insufficiently oxygenated blood since the lungs are not processing oxygen sufficiently. Other causes of anemic anoxia might include chronic anemia, acute hemorrhage and carbon monoxide poisoning.

Toxic anoxia occurs when a sufficient amount of oxygen is available within the bloodstream but the tissue is unable to accept and utilize it.

Stagnant anoxia (also called hypoxic ischemic injury or HII) is an internal condition that blocks sufficient oxygen-rich blood from reaching the brain. This includes strokes, cardiac arrhythmia and cardiac arrest.

Anoxic anoxia is caused when there is not enough oxygen in the air for the body to benefit with it. This can occur at high altitudes.

Common causes of anoxia

- Respiratory arrest
- Electrical shock
- Drowning
- Heart attack
- Brain tumors
- Heart arrhythmia
- Extreme low blood pressure
- Carbon monoxide inhalation
- Poisoning
- Choking
- Compression of the trachea
- Respiratory conditions which interfere with proper breathing
- Suffocation
- Illegal drug use

Cognitive problems with anoxia may include some, all and other symptoms such as short-term memory loss, poor performance in executive functions (such as time management, attention, focus, planning and organizing), difficulty using words or processing what words mean or visual disturbances.

Physical problems might include lack of coordination, an inability to do common tasks, movement disorders (such as jerky movements or trembling), weakness in all four

limbs (quadriplegia), headaches, confusion, depression, hallucinations, delusions, personality changes and the inability to concentrate.

Jaden Small has anoxic brain injury and has trouble processing visual information. She often reaches for an object but is not able to touch it because she continues to reach in the wrong place. She also is unable to remember how to perform common tasks like how to drink from a cup or how to brush her hair. How might you support Jaden?

Traumatic Brain Injury (TBI)

Traumatic Brain Injury (TBI) can happen to anyone, anywhere. Injuries can range from mild to severe and the majority of cases are concussions or mild TBI. Most cases are treatable and there are ways to help prevent re-injury.

Understanding a brain injury can help you provide better care for the individuals you care for.

Risk

Anyone can get a TBI and some people have a higher risk.

Some facts:

- About twice as many males as females have a TBI.
- Risk is highest for young people up to 19 years of age and people over 65 years old. However, all ages have TBIs.
- There is a higher incidence of TBI in Native American and Alaskan Native communities than in the general population. Nationally, African Americans have the highest death rate from TBI.
- People who have had a TBI before are at higher risk of having another.

(Traumatic Brain Injury Strategies for Surviving and Thriving, DSHS)

Some activities place people at higher risk for a TBI. According to the Centers for Disease Control, the main causes of TBI are:

- Falls
- Motor vehicle crashes
- Events that cause the head or body to be struck, including many kinds of sports
- Violent assaults
- Domestic violence
- Military duties – blasts are now a leading cause of TBI for active military personnel in war zones

Concussion

A concussion is the most common type of brain injury caused by a bump, blow, or jolt to the head or by a hit to the body that causes the head and brain to move rapidly back and forth. This sudden movement can cause the brain to bounce around or twist in the skull, creating chemical changes in the brain and sometimes stretching and damaging brain cells.

Concussions are serious. A concussion may not be life threatening, although the effects of a concussion can be serious.

The brain is complex and every brain injury is different. Some symptoms may appear right away, while others may not show up for days or weeks after the concussion. Sometimes the injury makes it hard for people to recognize or admit that they are having problems.

Signs of concussion may be subtle. Early on, problems may be missed by the individual, family, friends or doctors. People may look fine even though they are acting or feeling differently.

Because all injuries are different, so is concussion healing. Most people with mild injuries heal fully, but it can take time. Some symptoms can last for days, weeks or longer.

In general, healing is slower in older persons. Persons who have had a concussion in the past may find that it takes longer to recover from a new or current injury.

Brain cell damage

Tearing of brain cells (axonal shearing). When the head or body is hit or jerked, the brain can slam back and forth inside the skull. Because the brain is soft and jello-like, it is pressed and stretched inside the skull. A vital portion of the fragile brain cells (called neurons) may be stretched to a point of tearing. This is known as axonal shearing. When this happens, the damaged brain cells die. When a neuron dies it disintegrates releasing chemicals which destroy nearby neurons.

Bruising and bleeding (contusion). When the brain slams against the inside of the skull, small blood vessels can be torn. Bruising and bleeding can cause death of brain cells.

Skull fracture. When skull bones are cracked or broken, they may press on the brain or penetrate it with pieces of bone.

Coup-contracoup (pronounced coo-contracoo).

Damage can occur both at the spot where the head is struck (coup) and directly opposite (contracoup), due to the forward and backward motion of the brain inside the skull as in a “whiplash” accident.

Secondary Events – The body’s response to trauma

Brain swelling (edema). After an injury, the brain swells just like any other injured body part. Swelling inside the skull can cause damage by squeezing brain cells or interrupting flow of blood and oxygen to brain tissue. Severe swelling can press on the brain stem and cause death.

Blood pooling (hematoma). If damaged blood vessels are large, they may make a pool of blood inside the skull and increase pressure on the brain. Surgery may be needed to drain blood out of the skull.

Shock. Loss of blood to the brain, due to the body’s shock response, may rob the brain of oxygen (see anoxia) and injure brain tissue.

Warning Signs

In rare cases, a dangerous collection of blood may form on the brain that may squeeze the brain against the skull. Call 9-1-1 right away or contact a medical professional or emergency department if one or more of the following signs after a bump, blow, or jolt to the head or body:

- One pupil larger than the other.
- Drowsiness or inability to wake up
- A headache that gets worse or does not go away
- Slurred speech, weakness, numbness, or decreased coordination
- Repeated vomiting or nausea, convulsions or seizures (shaking or twitching)
- Unusual behavior, increased confusion, restlessness, or agitation
- Loss of consciousness (passed out/knocked out). Even a brief loss of consciousness should be taken seriously.

Symptoms

Most people with a concussion have one or more of the symptoms listed below and fully heal within days, weeks or a few months. For some, the symptoms of concussion can last even longer.

Concussion symptoms are changes to an individual’s baseline (what is normal to the individual) and often grouped into four categories including:

Remembering and thinking

- Difficulty thinking clearly
- Feeling slowed down
- Difficulty concentrating
- Difficulty remembering new information

Physical

- Headache
- Nausea or vomiting (early on)
- Balance problems
- Dizziness
- Fuzzy or blurry vision
- Feeling tired, having no energy
- Sensitivity to noise or light

Emotional/Mood

- Irritability
- Sadness
- More emotional
- Nervousness or anxiety

Sleep disturbance

- Sleeping more than usual
- Sleeping less than usual
- Trouble falling asleep



Older Adults

Because concussions are often missed or misdiagnosed among older adults, be especially alert if you know that an older adult has fallen or has a fall-related injury such as a hip fracture. The focus of the medical treatment team may have been on the hip fracture and not take into account the individual also hit their head. Older adults may have a higher risk of serious complications from a concussion, such as bleeding on the brain. Headaches that get worse or increased confusion are signs of this complication. Older adults often take blood thinners; if they do, they should be seen immediately by a health care provider if they have a bump or blow to the head or body even if they do not have any of the symptoms listed above.

In pairs, select one symptom from each category and discuss ways that you might support an individual **who has all four of the symptoms**. Be prepared to share with the class.

Remembering and thinking

Physical

Emotional/Mood

Sleep disturbance

Severity

Medical professionals use some common severity scales to describe TBIs. They may rate a TBI as “mild”, “moderate”, or “severe” based on: whether the person lost consciousness, for how long and other criteria. A severity rating is necessary for medical professionals to record the injury right after it happens, decide on medical treatments, track changes following treatments and get paid for medical services. Early severity ratings have been found not to be very good at predicting problems that may develop later or how much time or what the path will be to recovery.

Over time, a TBI survivor may do better or worse than predicted at first. Some reasons include:

The problems (symptoms) will be different depending on whether damage is focal (focused in one or a few limited areas), or diffuse (spread throughout the brain).

Complicated interactions take place among different parts of the brain. Parts of the brain that have less damage, or that recover quickly may try to take over for a more damaged part with unpredictable results.

All head injuries should be taken seriously. It is not your job to evaluate or diagnose. When in doubt, have a doctor check it out.

Mild

Mild

An individual with mild traumatic brain injury is a person who has had a traumatically induced physiological disruption of the brain function, as manifested by at least one of the following:

- Any period of loss of consciousness

- Any loss of memory for events immediately before or after the accident
- Any alteration in mental state at the time of the accident (eg, feeling dazed, disoriented or confused); and focal neurological deficit(s) that may or may not be transient; but where the severity of the injury does not exceed the following:
 - Loss of consciousness and/or confusion and disorientation for 30 minutes or less;
 - After 30 minutes, an initial Glasgow Coma Scale (GCS) of 13-15; and
 - Posttraumatic amnesia (PTA) not greater than 24

A mild TBI may also be referred to as a concussion. It is estimated that up to 75 percent of TBIs are initially rated as mild (Traumatic Brain Injury Strategies for Surviving and Thriving, DSHS).

Possible Signs and Symptoms

Physical symptoms

- Difficulty sleeping
- Dizziness or loss of balance
- Fatigue or drowsiness
- Headache
- Loss of consciousness for a few seconds to a few minutes
- Nausea or vomiting
- No loss of consciousness, but a state of being dazed, confused or disoriented
- Problems with speech
- Sleeping more than usual

Sensory symptoms

- Sensitivity to light or sound
- Sensory problems, such as blurred vision, ringing in the ears, a bad taste in the mouth or changes in the ability to smell

Cognitive or mental symptoms

- Feeling depressed or anxious
- Memory or concentration problems
- Mood changes or mood swings

Branden Fuller received a diagnosis of “just a concussion” after a car crash. Does this mean that you should not take Branden’s injury seriously?

Moderate

Moderate

Moderate TBI is defined as loss of consciousness lasting between 15 minutes and a few hours, followed by a few

days or weeks of mental confusion. About 10-15 percent of TBIs are rated moderate (Traumatic Brain Injury Strategies for Surviving and Thriving, DSHS).

Severe

Severe

Severe TBI is defined as loss of consciousness for six hours or longer, either immediately after the injury or following a period of clarity. Less than 10 percent of all TBIs are rated severe (Traumatic Brain Injury Strategies for Surviving and Thriving, DSHS). People who remain unconscious for a very long time may be described as in a coma or permanent vegetative state.

Moderate to Severe Signs and Symptoms

Moderate to severe traumatic brain injuries can include any of the signs and symptoms of mild injury, as well as these symptoms that may appear within the first hours to days after a head injury:

Physical symptoms

- Clear fluids draining from the nose or ears
- Convulsions or seizures
- Dilation of one or both pupils of the eyes
- Inability to awaken from sleep
- Loss of consciousness from several minutes to hours

- Loss of coordination
- Persistent headache or headache that worsens
- Repeated vomiting or nausea
- Weakness or numbness in fingers and toes

Cognitive or mental symptoms

- Agitation, combativeness or other unusual behavior
- Coma and other disorders of consciousness
- Profound confusion
- Slurred speech

Ricky Fletcher has had moderate TBI from an accident he experienced in the military. The event happened many years ago and Ricky still has difficulty completing tasks that were once routine. It takes longer for him to think about his responses and has a hard time thinking and remembering many things. How might you support Ricky in his independence?

Common scales for rating TBI include:

- The Glasgow Coma Scale (GCS) – Used to measure different states of alertness, motor and verbal functions following a brain injury. The lowest possible GCS score is three for a person in a deep coma. The highest score of 15 is for a fully awake person.
- The Rancho Los Amigos Scale – Used to track progress of a TBI survivor during rehabilitation.

Handout

Problems brain injury can present to activities of daily living

- Anxiety or depression
- Confusion
- Decreased awareness of one's own challenges
- Decreased control over the right or left side of the body
- Difficulties in producing language, such as through speaking or writing
- Difficulties in understanding spoken and written language
- Difficulties remembering language
- Difficulty initiating activity – not “self-starting”
- Difficulty locating where objects are in space through vision
- Difficulty perceiving size, shape and color
- Impaired logic and judgment
- Impaired thinking in all areas
- Lack of attention (awareness) to anything on and including the left side of the body (“left neglect”)
- Lack of awareness of one's limitations
- Lack of coordination of physical movements
- Loss of the “big picture”
- Problems maintaining physical balance
- Problems with planning body movements
- Problems with sequencing (understanding and carrying out step-by-step actions in the right order)
- Problems with skilled motor activity, such as finger movements, using tools
- Problems with visual perception that cause poor hand-eye coordination
- Reduced thinking speed
- Visual memory problems such as not remembering a friend's face



Possible Effects of the Injury

Apraxia

Apraxia is a motor disorder caused by damage to the brain in which the individual has difficulty or loss of ability to plan or perform tasks or movements when asked.

Apraxia is most often due to a lesion located on the dominant (usually left) hemisphere of the brain.

Strategies include:

- Speech therapy
- Occupational therapy
- Physical therapy

With therapy, some patients improve significantly, while others may show very little improvement. Many people with apraxia are no longer able to be independent. No medication is currently shown useful for treating apraxia as of the printing of this publication.

Attention and memory

A person with a TBI may be unable to focus, pay attention, or attend to more than one thing at a time. Since attention skills are considered a building block to higher level skills such as memory and reasoning, people with attention or concentration problems often show signs of other cognitive problems as well.

Strategies to improve attention and concentration:

- Try to decrease distractions
- Focus on one task at a time
- Begin practicing attention skills such as reading a paragraph or adding numbers in a quiet room
- Gradually make tasks harder
- Take breaks when tired

Behavioral and emotional changes (more later)

Individuals who have had TBI often experience changes in behavior as well as emotional difficulties. Common behavior changes include frustration, impulsivity, less effective social skills and impaired self-awareness. Frequently experienced emotional difficulties include depression, anxiety and mood swings.

See more information on behaviors in Module 3.

Bladder and bowel changes

Bladder and bowel functions are controlled by the brain and nervous system. For many people with a TBI, bowel and bladder functions are impaired in the early days to weeks following injury. Healthcare providers expect this and are prepared to help. A urinary catheter (a tube placed in the body to collect and drain urine from the bladder) and use of diapers or pads may be needed.

This might look like:

- Loss of bladder or bowel control
- Increased urgency to urinate
- Incomplete bladder or bowel emptying
- Increased bladder infections
- Constipation
- Not recognizing the need to urinate/defecate or recall when they last did
- Skin problems due to incontinence

Bowel and bladder retraining are part of the rehabilitation process. Fortunately, with time and practice, most people with a TBI regain control of these body functions.

Strategies for bladder training may include:

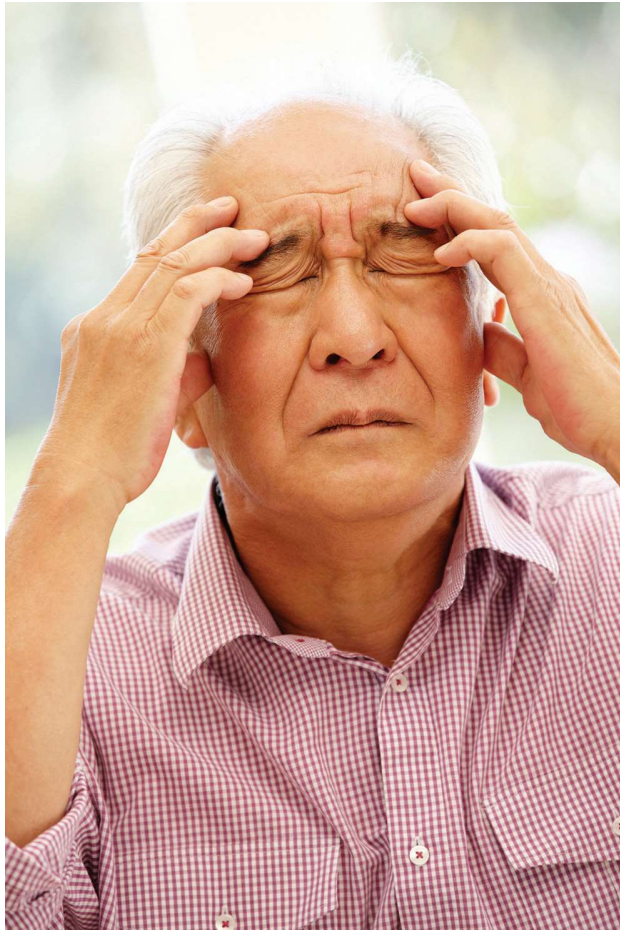
- Specific fluid schedule
- Limiting fluids in the evening and timed attempts to empty the bladder

Strategies for bowel training may include:

- Scheduled attempts
- A high-fiber diet
- Adequate fluids
- Physical activity
- Eating meals at regular times
- Use of medications.

Dizziness and balance

Dizziness may make a person feel unsteady and like things are moving when they are not.



Symptoms of dizziness may include the sensation of rotation, spinning or movement, feeling unsteady or like you are losing your balance or feeling hazy or like you are about to faint or pass out.

The biggest concern about dizziness is the increased tendency to fall when dizzy or lightheaded. During the weeks that follow a TBI, a majority of people will recover from dizziness and other associated symptoms.

This may present as complaints that the surroundings are spinning or moving, loss of balance or unsteadiness, nausea, wooziness or lightheadedness and possibly blurred vision during quick or sudden head movements.

Strategies for supporting:

- Encourage the individual to drink plenty of water to stay well hydrated.
- Avoid or decrease alcohol and caffeine intake.
- Have the individual sit upright for a few minutes before walking to give the brain and heart enough time to adjust to the change of body position.
- Encourage the individual to sit or lie down as soon as they feel dizzy and avoid sudden movements or bending over.

Also, make sure the environment is fall-proof by removing area rugs and electrical cords that could cause someone to slip or trip. Use non-slip mats in the bath and shower floors.

Fatigue

Fatigue is a common complaint among people with a TBI and often occurs in conjunction with sleep disturbances. The body needs a large amount of metabolic energy for healing after traumatic injuries. Fatigue is also a major contributor to falls and problems with emotion. It is a critical piece to be aware of as it makes all the other symptoms worse.

Patterns of rest and activity are often very different for many weeks to months after a TBI. Fatigue affects an individual both physically and mentally. They may have to work harder to learn, stay focused and improve their ability to concentrate. Fatigue may also lead to feelings of irritability, headaches and other bodily aches and pains.

This may present as being frequently tired, lacking energy, poor stamina and slower thinking speed.

Strategies to help an individual experiencing fatigue may include:

- Set regular times for recharging
- Decrease stimuli
- Allow the brain to recover from accepted fatigue
- Supporting a safe, regular exercise program
- Set up a daily schedule
- Reduce demands
- Schedule important activities and appointments for the times of day when the individual is most awake
- Be aware of the signs of fatigue and ask the individual to do the same

Physical

Physical fatigue can come from muscle weakness. The body needs to work harder to do things that were easy before the TBI. Physical fatigue gets worse in the evening and is better after a good night's sleep. Often this kind of fatigue will lessen, as the individual gets stronger, more active and back to his or her old life.

Mental

Mental (cognitive) fatigue comes from the extra effort it takes to think after your brain is injured. Many common tasks take much more concentration than they did before. Working harder to think and stay focused can make you mentally tired.

Emotional

Emotional (psychological) fatigue is associated with depression, anxiety and other psychological conditions. This type of fatigue gets worse with stress. Sleep may not help at all and the fatigue is often at its worst when you wake up in the morning.

What can you do to help decrease fatigue for the individual(s) you care for?

Headaches

Headaches are common following a TBI. The individual may have experienced headaches prior to the TBI, however they may worsen due to fatigue, stress or a history of headaches. Some people may have a headache all the time, and some headaches come and go. Treatment plans should be developed for each individual.

Headaches might present as pain in the head or neck, sensitivity to light, sensitivity to sound, nausea and/or poor concentration.

You can assist the individual by asking the person to lie down in a dark and quiet place to relax and promote sleep or rest. You can also use heat or ice on the forehead or neck and avoid bright lights. Sleep masks may help to further block out light.

List other ways that you can help an individual who may be experiencing headaches.

Muscle weakness/ immobility

Muscle movement originates in the brain so a TBI may affect a person's movement. The left side of the brain controls movement of the right side of the body and movement on the left side of the body is controlled by the right side of the brain.

You may see muscle weakness on only one side of the body. You may also see total loss of the ability to move and feel (paralysis) of the arm, leg or trunk on one side of the body. This combined with balance issues can be a big contributor to falls. Often the individual may be unaware of his/her weakness or paralysis.

A physical or occupational therapist will develop leg and arm exercises to help strengthen muscles and prevent joint tightness. Help support these exercises as part of the care plan. Allow extra time to perform daily activities. Encourage use of prescribed assistive devices such as walker or cane. Check skin daily for pressure points caused by any splints, assistive devices or body positioning.

Pain

Pain after a TBI can be acute or chronic. Pain may be musculoskeletal, neuropathic (nerve pain), or secondary to medical complications. Individualized pain management is required for individuals with TBI.

Strategies:

- Always follow medical/therapeutic recommendations
- Look for symptoms of pain
- Modify activity and/or environment



Post-Traumatic Stress Disorder (PTSD)

Some individuals will have a dual diagnosis of TBI and PTSD. Symptoms of PTSD include unwanted and repeated memories of a life-threatening or traumatic event, flashbacks where the event is relived and a person temporarily loses touch with reality, avoidance of people, places, sights or sounds that are reminders. Symptoms also may include feelings of detachment from people, even family and emotional numbness, shame about what happened and what was done or even survivor guilt with loss of friends or comrades. Symptoms may also include hypervigilance or constant alertness for threats.

When PTSD and TBI coexist, changes in cognition such as memory and concentration, depression, anxiety, insomnia and fatigue are common with both diagnoses. One feeds and reinforces the other so it is complicated. Compounding synergy between these two comorbidities necessitates careful evaluation and treatment.

Be aware that a person with TBI and PTSD may be at very high risk for suicide. See page 21 for more information on suicide.

Lucy Peters has TBI resulting from her car hitting a semi-truck on I-5. She had a period of disorientation and confusion after her car crash and did not remember the events just before the crash. The disorientation lasted a few days. Lucy also has PTSD and is now having unwanted and continuing intrusive thoughts and memories of the crash. The memories keep her awake at night as she relives the crash over and over.

Discuss how you might support Lucy with this dual diagnosis.

Seizures

Seizures are a sudden, uncontrolled electrical disturbance in the brain. Seizures are common after a moderate or severe TBI, even in people who never had a seizure in the past.

This might look like shaking or jerking of the arms and legs, loss of consciousness (the person cannot be aroused or awakened) altered attention, emotion, sensation or bodily movement. The individual may lose bowel or bladder control. The individual experiencing a seizure may complain about strange odors or sensations (aura) in the body (such as buzzing or tingling in the arms, legs or face).

You can help during a seizure by keeping calm, avoid holding the individual down or trying to stop body movements. Put something flat and soft under the head such as a blanket or a pillow. If able, clear the space around the individual to avoid additional injury during seizure. Once the seizure is over, turn the person gently onto one side, this helps to keep the airway clear. Do not try to force the mouth open or hold the tongue and do not put anything in the mouth. Stay with the individual until the seizure ends completely and they regain consciousness or awareness of their surroundings.

Call 911 if the individual experiences:

- Difficulty breathing during or after a seizure.
- If the seizure lasts more than one minute.
- A second seizure that happens immediately after the first seizure.
- Difficulty waking up from the seizure or a second seizure without waking up in between.

There will be memory loss after a seizure. Expect confusion and gently tell the individual they have had a seizure and re-orient them.

Sensory changes

The brain is the center for all five of our senses: sight (vision), hearing, taste, smell and touch. When the brain is injured, any of these senses may be affected. The location of the brain injury and how severe the injury is determines which, if any, of the five senses that may be impaired.

This might present as vision changes (blurry vision, double vision, decreased vision or sensitivity to light), hearing changes (muffled hearing or ringing in the ears), changes in taste and smell (altered taste, metallic flavor in the mouth, decreased ability to smell, complete lack of taste and smell).

For some sensory changes, interventions like physical or occupational therapy might be helpful to improve symptoms. Sensory changes can continue to improve over the first several months or even years after a TBI.

What are ways to support someone with sensory changes in each of the five senses?

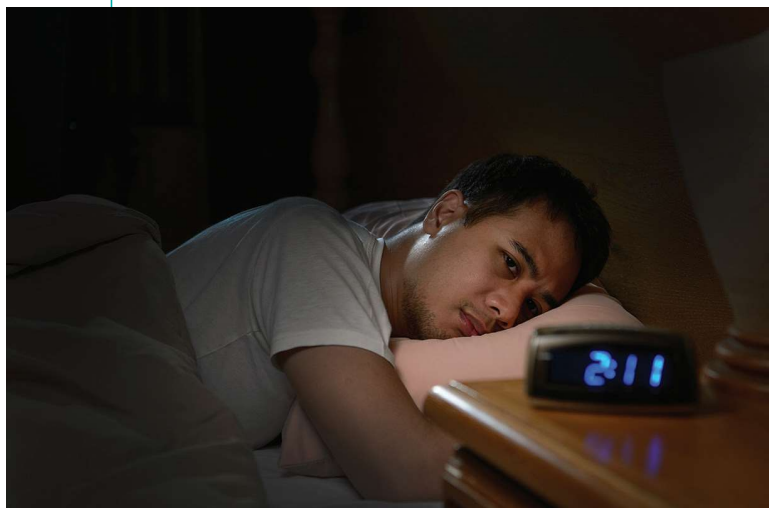
Sight:

Hearing:

Taste:

Smell:

Touch:



Sleep

Altered sleep patterns are very common after TBI. This problem is usually worse in the first several weeks to months after injury.

Many people with a TBI sleep during the day and are awake at night. They may now nap routinely, even if they did not before the injury.

Individuals with sleep disturbances or insomnia might have difficulty falling or staying asleep (this is known as insomnia), may be awake at night and sleep during the day, take frequent naps or sleep too much or too little.

To support an individual with sleep disturbances, establish a very specific daily routine, encourage the individual to avoid or decrease napping, caffeine and alcohol.

Create a list of more ways you can help support an individual who has sleep disturbances or insomnia.

Spasticity

An injury to the brain can cause an abnormal increase in muscle tone causing stiffness or tightness. This is called spasticity. A spastic muscle does not easily relax the way a normal muscle does. This is most common with severe and/or penetrating brain injury.

This might present as involuntary muscle tightness and stiffness, decreased range of movement and abnormal positioning of the arm, legs or body.

You can help support the individual by encouraging a stretching program developed by a physical or occupational therapist. You might also post diagrams of stretches that can be done regularly. Monitor the individual for any pressure points from any splints used to help control spasticity.

Swallowing, appetite and weight

Many people with traumatic injuries do not drink or eat normally for a period of time after the injury. As a result, they lose weight. It is important to fully evaluate swallowing before the individual drinks or eats. The purpose of evaluating the person's ability to swallow is to make sure that what they eat goes into the stomach, not into the lungs. When food or fluid slips into the lungs, it often results in pneumonia.

Most people do best with food texture between fluid and very chewy. With practice, most people will return to a normal diet.

Appetite can be impacted because of a TBI. Some have reduced appetite while others gain weight due to boredom, memory problems and an increased appetite.

Watch for:

- Choking
- Coughing
- Difficulty swallowing during meals
- Pocketing food inside the mouth
- Drooling
- Decreased interest in eating
- Weight loss without trying to lose weight

- Overeating, resulting in weight gain or memory problems
- Failing to remember when to eat or when they last ate

You can provide support by working with therapists and dietitians to learn what foods are allowed and to assist as needed in drinking and eating. Special strategies for eating may be needed such as encourage eating slowly, chin tucks during swallow, double swallow, adding thickeners to food and follow every bite with fluid.

How would reduced taste and smell following a TBI influence appetite and weight? What are some strategies you can use to support this individual?

Visual problems

The ability to process and understand sensory information from the eyes takes place in the brain. The eyes transmit information from the environment through the optic nerves to the part of the brain that determines what the person is actually seeing. A TBI can affect this area of the brain or the optic nerves, resulting in blind spots, vision loss and/or changes in the brain's ability to understand what the eyes see.

Spatial awareness could also be a problem. This is when the individual's ability to perceive where they are in space in relation to other items in the environment.

This might present as a tendency to ignore things on one side of the body, bumping into things on the affected side, difficulty in finding way around, especially in new places, difficulty with recognizing shapes and telling the difference between shapes.

You can support an individual with visual problems by reminding the individual to look around the environment, use visual cues and try not to move familiar items.

Lesson Summary

- Acquired Brain Injury (ABI) is damage to the brain, which occurs after birth and is not related to a congenital or degenerative disease.
- Traumatic Brain Injury (TBI) can range from mild to severe and the majority of cases are concussions or mild TBI.
- When the brain is injured, it may be injured in one or more areas. Injury to the brain in various areas and to various degrees contributes to each individual case of TBI being unique.
- There are may be possible effects of brain injury. No two brain injuries are the same.

Checkpoint

Instructions: Read each scenario below and choose the best answer to the question that follows the scenario.

Scenario

Name: Lucy Peters | Age: 65

Scenario: Lucy has a brain injury resulting from her car hitting a semi-truck on I-5. Lucy is experiencing problems with her vision and having difficulty finding her way around. She will often bump into things on her right side. She is also having difficulty swallowing during meals. How might you help Lucy Peters?

- A. Support Lucy to cook her own food.
- B. Encourage Lucy to start a stretching program and decrease napping.
- C. Remind Lucy to look around her environment and to eat slowly.
- D. All of the above.

Name: Ricky Fletcher | Age: 61

Scenario: Ricky has a moderate TBI from an accident he experienced in the military. Ricky is experiencing difficulty falling asleep and staying asleep. He is awake frequently at night and falls asleep during the day. He is also experiencing muscle stiffness (spasticity) and decreased range of motion in his arms and legs. How might you help Ricky Fletcher?

- A. Support Ricky to decrease distractions and reduce demands.
- B. Encourage Ricky to start a stretching program and decrease napping.
- C. Remind Ricky to look around his environment and to eat slowly.
- D. All of the above.

Name: Branden Fuller | Age: 56

Scenario: Branden was in a car crash and diagnosed with a concussion. Branden is experiencing problems with attention and memory. He is frustrated that he is unable to focus on more than one thing at a time. He is also experiencing more fatigue than usual. How might you help Branden Fuller?

- A. Support Branden to decrease distractions and reduce demands.
- B. Encourage Branden to start a stretching program and decrease napping.
- C. Remind Branden to look around his environment and to eat slowly.
- D. All of the above.



Module 2: Brain Injury Management

The caregiver will recognize and identify strategies to provide individualized quality care and management of symptoms for individuals with brain injury.

Module 2: Brain Injury Management

Objective

The caregiver will recognize and identify strategies to provide individualized quality care and management of symptoms for individuals with brain injury.

Overview

It is hard to know exactly what will happen following a TBI because an early rating of the brain injury may not tell you much about what can happen long-term. It is also impossible to predict all possible effects of damage because interactions within the brain and body are complex and change over time.

Factors such as the amount of time that has passed since the injury, the amount of time between the injury and diagnosis as well as personality type and learning style (before and after injury) make the injury unique to each person and may affect the recovery process.

Additional factors that make each TBI unique:

- General physical and mental health before and after the injury.
- Poor physical health and co-existing mental health or substance abuse problems usually make it more difficult to recover from a TBI.
- Chances of recovery are worse for adults who have had more than one brain injury, including childhood brain injuries.
- Psychological reactions to the trauma event, to injury and to having a new disability.
- Influences in the person's environment that help or hinder the recovery, including the person's support system.

Think about how a person's condition and abilities may change over time and remember not to rely too much on rating of severity that was done immediately following the injury.

Trauma Informed Care

Trauma Informed Care (TIC) is an approach that aims to engage people with history of trauma, recognize the presence of trauma symptoms and acknowledge the role

that trauma has played in their lives. Many people have had some level of trauma in their past. TIC is not about treating the trauma or symptom management. Instead, TIC is about gathering information about each individual you care for and about potential trauma the individual has experienced. TIC is about remaining sensitive to issues or behaviors the individual might have related to past trauma.



The focus is on what has happened to the person rather than what is wrong with the person. Instead of asking what is wrong with you? Ask what has happened to you and how can I support you?

Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life-threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional or spiritual well-being (SAMHSA, 2014).

Are there ways you or your organization is trauma informed? Are there ways that you or your organization can be more trauma informed? What challenges might you have implementing a trauma informed approach?

Approach

With a TBI, there is no cookie cutter approach to recovery and support. This means that every TBI is approached individually. If you have seen one brain injury, you have seen one brain injury. Always use the approach that each brain injury is unique, with unique characteristics and each injury will be different.



Person-Centered Approach

Consider the kind of person you are and your values and discuss ways that you would want to receive personalized care if you had a brain injury.

When providing care, it is important to remember that each person is a unique and worthwhile individual. This uniqueness comes from a lifetime of experiences influenced by many things. This includes cultural background, religious upbringing and beliefs, gender and gender identity, sexual orientation and/or marital status, economic status, social groups, disability, how a person sees the world, what he/she believes in and values, as well as what he/she considers acceptable ways to look and act and what he/she considers “normal.”

Your reactions and feelings towards others – especially those different from what you consider “normal” – happen automatically based on beliefs and values learned from your own upbringing (culture). These are biases. Hidden biases can influence how you talk, look at and do things for those individuals you care for.

It is important to be aware of and question how your beliefs and values influence your interactions with others. Differences are neither good nor bad. The way you react to the differences is key. Quality of life is subjective to each individual. Quality defined by one person may not be how another person defines quality.

Get to know the individual as a unique individual.

What is important to a person and what is important for a person?

It is often easier to learn what is important for a person – health, safety, being a valued member of the community (status and appropriateness).

It takes careful thinking and asking particular questions to get at what is important to someone - comfort, happiness, contentment, fulfillment, satisfaction, purpose.

It is important to have a balance between what is important to and what is important for an individual.

Pair up, discuss, and write what is important to you and how this would look like to receive the best supports if you were a brain injury survivor.

How would you feel if you receive no support in what is important to you?

Person-centered language



When interacting with people, it is important to remember to use person-centered language. Person-centered language is about communicating in a respectful and considerate manner. It is preferred to name the person first and the condition second. You should avoid identifying a person as their disability first.

Are the phrases below preferred methods of communication with someone who has a brain injury or should you avoid using the phrase? On the line provided, write a **P** for preferred communication or an **A** for avoid.

- ___ I am a caregiver for a brain-damaged woman.
- ___ Sherry has a traumatic brain injury.
- ___ Raphael is a person with TBI.
- ___ Brain injury victim Inga.
- ___ The brain injured person named Don.
- ___ Edward is a survivor of a brain injury.

Enhancing Recovery and Healing Process

Recovery is not a smooth process for most people. Sometimes people will get better for a while and then have a set back or stop making progress. Plateaus or taking a few steps backwards is normal for the recovery

process. New problems and stresses can arise and slow progress as well. New stresses may or may not relate to the brain injury.

Physical

A period of confusion and disorientation often follow a TBI. The person's ability to pay attention and learn steps may be lower. Agitation, nervousness, restlessness or frustration may appear. TBI may cause disrupted sleep patterns. The person may overreact to stimulation and become physically aggressive. This stage can be disturbing because the person behaves so uncharacteristically.

Inconsistent behavior is also common. Some days are better than other days. For example, a person may begin to follow a command (lift your leg, squeeze my finger) and then not do so again for a length of time. This stage of recovery may last days or even weeks for some. In this stage of healing, try not to become anxious about inconsistent signs of progress. Difficulties during this stage of recovery are normal.



Later stages of healing can bring increased brain and physical function. The person's ability to respond may also improve gradually.

Short term (6-9 month) / Recovery or stabilize

The fastest improvement happens in about the first six months after injury. During this time, the injured person will likely show many improvements and may seem to be steadily getting better. The person continues to improve between six months and two years after injury and this varies for different people and may not happen as fast as the first six months. Improvements slow down significantly after two years. However, they may still occur many years after injury. Most people continue to have some problems, although they may not be as bad as they were early after injury. Rate of improvement varies from person to person.

Long-term potential

Based on information of people with moderate to severe TBI who received acute medical care and inpatient rehabilitation services, two years post-injury:

Most people continue to show decreases in disability.

- 34% of people required some level of supervision during the day and/or night.
- 93% of people are living in a private residence.
- 34% are living with their spouse or significant other; 29% are living with their parents.
- 33% are employed; 29% are unemployed; 26% are retired due to any reason; and 3% are students.

Sensory hypersensitivity

Sense of touch, taste, smell, hearing or vision is extra sensitive or heightened after a brain injury. Sensory hypersensitivities are a major contributor to fatigue and overload. The senses may experience more information than an injured brain can process and organize.

Some examples of sensory hypersensitivities may include:

- Sounds are alarming and may startle.
- It may feel like the individual has megaphones in their ears.
- Background sounds and stimulating environments become overwhelming.
- Fluorescent and bright lights give headaches.
- Clothing may feel irritating and uncomfortable
- Large gatherings of people feel overwhelming.

Person-centered strategies to help:

- Limit exposure to avoid sensory overload.
- Avoid sensory overload by avoiding crowds or places where there is excessive stimuli.
- Plan activities when things are quiet – early in the week, early day shopping and errands, shop in smaller stores, eat between regular meal times, etc.
- Complete a sensory diary/evaluation of the persons living situation and daily activity.
- Look at what the individual is exposed to and reduce or change the stimuli to a more soothing type.

Strategies for sensitivity to sound:

- Limit exposure and participation in activities considered noisy.
- Use or carry earplugs or headphones.
- Add a fan, white noise or soothing music for background sound.

- When anxious or overwhelmed, encourage closing eyes, taking slow deep breaths.
- Gradual exposure to sounds and increase tolerances.

Strategies for sensitivity to light:

- Avoid bright lights and fluorescent lights.
- Use sunglasses or hats even indoors.
- Try tinted or polarized sunglasses.
- Try FL-41 (Fluoride) coated eyewear.
- Encourage more orange colored fruits and vegetables (carrots, sweet potatoes, squash, and cantaloupe).
- Encourage closing eyes when feelings of stress or anxiety surface.

Strategies for sensitivity to touch, taste and smell:

- Rub different textures on the arms, increasing intensity that may gradually decrease sensitivities.
- Add texture, contrasting temperatures and flavors to foods.
- Take note on how different aromas make the individual feel.
- If the individual has an altered sense of smell, regularly make sure that all of the smoke and gas detectors are functioning.

Allowing time for rest is important to help recharge the brain. Techniques such as meditation are helpful when used regularly to help calm the individual and help self-regulate during sensory overload.

Additional considerations

Stress

A TBI can cause sudden, unexpected and drastic changes in the lives of survivors and others who support them. This can add a great deal of stress. Managing stress effectively is important for wellbeing.

Stress is a part of daily life for most everyone. After a life-changing event like a TBI, it is normal to feel intense stress.

Stress is the body's reaction to harmful situations whether real or perceived. During stress response, your heart rate increases, breathing quickens, muscles tighten and blood pressure rises.

Stress means different things to different people and some people are better able to handle stress. Stress in small doses can help you accomplish tasks and prevent you from getting hurt.

Stress can affect all aspects of life including emotions, behaviors, thinking ability and physical health. No part of the body is immune. Since people handle stress differently, symptoms of stress can vary.

Sustaining a TBI can be stressful for a number of reasons, including the potential for:

- Potential loss of a support system
- Potential loss of job/income
- Increased psychological stress
- Change of roles within the family unit
- Decreased ability to focus
- Decreased ability to function

Discuss ways that stress can affect emotions, behaviors, thinking ability and physical health. Discuss ways to support the individuals you care for to reduce stress.

Dual Diagnosis (pre or post injury)

A dual diagnosis means having two different conditions at one time. Other terms for dual diagnosis are co-morbidity, co-existing disorders or dual-disability.

Substance use disorder

Many people who incur a TBI have a substance abuse problem prior to injury and a number of people continue to experience a substance problem after the TBI.

In addition to the large number of individuals who had substance use disorder before their injury and return to those levels after, some studies have shown that between 10% and 20% of persons with TBI develop a substance use problem for the first time after their injury (2010, BrainLine). Some people may turn to alcohol or drugs in hopes of finding some relief from pain, depression or anxiety. Often, these substances only compound the problem and may ultimately interfere with a person's recovery.



Mental health diagnosis

Some individuals will not only be coping with the effects of a brain injury, but also a mental illness. In addition to substance use disorders, mental illnesses such as depression, anxiety, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD), schizophrenia, bipolar disorder and personality disorders are possible dual diagnosis with a TBI.

The mental illness may be present prior to the brain injury and brain injury is a risk factor for developing a mental illness.

The effects of brain injury and mental illness can look very similar so misdiagnosis is possible if there are no clear medical records. The brain injury itself can cause symptoms similar to syndromes such as psychosis and dementia, which can increase chances of an incorrect diagnosis.

A mental illness can affect the rehabilitation process due to low motivation and creating negative coping mechanisms.

Dual diagnosis requires additional support and a holistic approach.

Select a mental health diagnosis and discuss possible challenges when the individual also has a brain injury. How might you support these challenges?

Developmental disabilities

Some individuals with a brain injury may also have a developmental disability.

Developmental disabilities are a group of conditions due to an impairment in physical, learning, language or behavior areas. These conditions begin during the developmental period, may influence day to day functioning and usually continue throughout a person's lifetime.

Developmental disabilities occur among all racial, ethnic and socioeconomic groups. Children and adults may have developmental disabilities such as Attention-Deficit/Hyperactivity Disorder (ADHD), autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, vision impairment and other developmental delays.

Select a developmental disability and discuss possible challenges when the individual also has a brain injury. How might you support these challenges?

Suicide

Suicide is a leading cause of death in the United States. In comparison to the general population, TBI survivors are at increased risk for suicide attempts and suicide deaths. The risk of suicide attempts increases after a



TBI if the individual also has a post-injury psychiatric/emotional disturbance and substance abuse problem.

Be aware of what can cause suicidal thoughts in people with TBI:

- Loneliness
- Lack of connection
- Holidays
- Lack of support
- Social anxiety
- Job/employment issues
- Lack of resources
- Frustration of tasks
- Bad news about prognosis

Things that may help:

- Psychotherapy
- Medication
- Support groups
- Having accessible providers
- Having a belief system – spirituality
- Distractions such as having something to do
- Having a responsibility such as a pet or a job
- Family/friends that care

Warning signs:

- Threatening to hurt or kill oneself
- Looking for ways to kill oneself: seeking access to pills, weapons, etc.
- Talking or writing about death, dying or suicide

Additional signs or other known risk factors:

- Hopelessness
- Feeling trapped – like there is no way out
- Increased alcohol or drug use
- Dramatic changes in mood
- Withdrawing from family, friends or society
- Anxiety, agitation, unable to sleep or sleeping all the time
- Rage, anger, seeking revenge
- Acting reckless or engaging in risky activities, seemingly without thinking
- No reason for living; no sense of purpose in life

Suicide Resources:

American Association of Suicidology:

www.suicidology.org

American Foundation for Suicide Prevention:

www.afsp.org

National Suicide Prevention Lifeline:

www.suicidepreventionlifeline.org

Suicide Prevention Resource Center: www.sprc.org

National Toll Free Numbers:

National Suicide Prevention Lifeline:

1-800-273-TALK (Text or call)

Washington Suicide Text “HEAL” to 754754

Discuss the warning signs of suicide and ways that you can help someone who may be thinking about suicide.

*Take a class dedicated to suicide and/or do additional research on suicide if you have not already.

Risky behavior

Risky behaviors are actions that are potentially detrimental to a person’s health or general well-being. Following a brain injury, many people experience impairments in their executive functioning, affecting their sense of judgment and insight. When the ability to make good choices is impaired, some people are particularly susceptible to the influence of friends and family. Peer influence can have positive and negative effects on individuals with brain injury.



Examples of risky behaviors:

- Alcohol abuse
- Smoking
- Abusing drugs
- Unprotected sex
- Multiple sex partners
- Driving under the influence of alcohol

Sometimes the best therapeutic intervention requires changing a person’s environment in ways that will limit exposure to risky behaviors.

Choose one of the risky behaviors listed or identify one not listed.

Discuss ways to support the individual who may be experiencing the risky behavior.

Medications

Choosing medications for individuals with a TBI requires caution. Some drugs slow recovery and no standard post-TBI treatment exists.

Many individuals with TBI are unusually sensitive to or intolerant of medication side effects. Some medications may not be as effective.



Treatment for a TBI is based on the severity of the injury. A mild injury might only require over the counter pain relievers to treat a headache.

Medications to limit secondary damage to the brain immediately after an injury might include diuretics, anti-seizure drugs and coma inducing drugs.

Medications may be used to treat symptoms of a TBI and to lower some of the risks associated with it.

- **Analgesics** may be used for pain relief and pain management.
- **Anti-Anxiety Agents** may lessen feelings of uncertainty, nervousness and fear.
- **Anti-Coagulants** may be used to prevent blood clots.
- **Anti-Convulsants** may be used to prevent seizures.
- **Anti-Depressants** may be used to treat symptoms of depression.
- **Anti-Psychotics** may be used to target psychotic symptoms of combativeness, hostility, hallucinations and sleep disorders.
- **Muscle Relaxants** may be used to reduce muscle spasms or spasticity.
- **Sedative-Hypnotic Agents** may be used to induce sleep or depress the central nervous system in areas of mental and physical response, awareness, sleep and pain.
- **Stimulants** may be used to increase levels of alertness and attention.

It is important for you to be aware of any new or worsening side effects from any medications.

Remember:

- Maintenance of a TBI is not recovery.
- Medications and dosages will need to be reassessed over time.

Polypharmacy

Polypharmacy is the use of multiple medications by an individual. In many instances, it can lead to negative outcomes or poor treatment effectiveness, often being more harmful than helpful or presenting too much risk for too little benefit. Concerns include increased adverse drug reactions, drug interactions, prescription cascade and higher costs. It is often associated with a decreased quality of life, including decreased mobility and cognition. The most common definition is five or more concurrent regular medications.

Strategy:

Have one pharmacist complete a medication review to assess for potential side effects and/or duplication of medications.

Discuss possible medication side effects. How would you support the individual experiencing these side effects? Discuss when you should call a healthcare provider or 911.

Quality of Life Therapies



Occupational

Occupational Therapists (OTs) specialize in improving a person's daily functioning by helping the individual to regain cognitive and motor skills and/or adapt to limitations through modification of tasks and/or the environment. They assist in areas of thinking and independent living skills such as dressing, bathing, cooking and managing money.

Assessment services provided by OTs include:

- Evaluation of abilities related to activities of daily living
- Dressing/grooming
- Eating
- Home management (cooking, cleaning)
- Functioning at work
- Evaluation of cognitive, motor and visual functioning as related to performance of functional activities

Interventions may include:

- Therapies to increase motor control for performance of daily activities.
- Guidance to person with TBI and family members regarding how to structure environments (at home) to reduce overstimulation for improved cognitive and physical function.

- Recommendations regarding equipment that will assist in doing daily activities (shower seat, adapted kitchen utensils) and training in the use of the equipment.
- Therapies to help persons with TBI use strategies to manage cognitive difficulties.

Speech

Speech-Language Pathologists (SLPs) specialize in evaluating and treating speech and language deficits, as well as problems with oral-motor functioning that can affect eating and swallowing.

A SLP provides assessment services such as evaluating speech and language skills, cognitive skills and oral motor function.

Speech and language skills

- Speech fluency
- Understanding and use of grammar and vocabulary
- Reading
- Writing
- Social communication skills

Cognitive Skills

- Memory
- Planning and organizing

Oral motor functioning

- Strength and coordination of muscles that control speech
- Strength and functioning of muscles that control eating and swallowing

Physical

Physical Therapists (PTs) specialize in providing treatment to improve mobility, relieve pain, reduce disability and promote health and fitness. PTs may improve strength, flexibility, balance and coordination. PT may also enhance functional mobility and increase independence in activities of daily living.

Some of the assessment services offered by PTs:

- Review of history
- Examine demonstrated abilities
- Assessment of perceptions of physical limitation and effects on daily life
- Determine diagnosis
- Develop a treatment plan

Music

Research shows that music is one of the best cognitive exercises. The brain engages in producing music and cognitive functions. The music permits restoration and alters brain functions.

Music helps improve sensory and motor functions, language and cognitive domains of functioning. It also has shown to improve executive functions along with improvement in emotional adjustment and decrease depression and anxiety following a TBI.

Different music will affect everyone differently. Music can be used to energize or relax. Try different types and watch for reactions.

Art

Art therapy helps build the self-awareness and self-esteem necessary to tackle various social situations and life challenges while increasing motor skills. Art therapy can help improve anxiety and depression. It can help reduce pain, stress and irritability.

Art therapy is a safe self-paced therapy done in a quiet setting. It can help concentration, memory, cognition and perception. An art therapist uses different aspects and techniques to target the benefits.

Dance/movement



Survivors of TBI face unique challenges of living in what can feel like a different body.

The American Dance Therapy Association (ADTA) defines dance/movement therapy (DMT) as the psychotherapeutic use of movement as a process which furthers the emotional, social, cognitive and physical integration of the individual.

Dance/movement therapy is one way to help brain injury survivors re-inhabit their bodies and cope with the emotional, cognitive and physical impairments that are often results of brain trauma.

This may involve eye contact, attuned breathing, verbal witnessing and touch. It may go slowly or quickly. Some dance therapy occurs in water.

A dance/movement therapist may address functional movement goals such as increasing range of motion and building physical strength.

Dance/movement therapists might also encourage TBI survivors to explore movement for the sake of expression, relaxation and to explore challenges and strengths. DMT can also help TBI survivors regain a sense of kinesthetic awareness or an internal sense and awareness of their bodies.

Yoga and meditation

Using mindful based practices can help strengthen the mind-body connection while also teaching the brain how to relax and allow itself to heal.

Adapted yoga may benefit survivors of a TBI and it may increase balance, balance-confidence, lower-extremity strength and endurance. Adapted yoga allows participants to experience movements even while sitting or in a wheelchair. Movements can start slow and increase with complexity as an individual is able.

Mindfulness meditation focuses on being present and aware of thoughts, feelings, emotions and sensations. Improved attention and self-regulation are possible through the process of meditation.

Kevin Pearce, a professional snowboarder and candidate for the 2010 Winter Olympics turned to yoga and meditation to contribute to his recovery after a life-changing TBI. He found that consistently attending yoga classes allowed positive changes to continue in his life. He and his brother Adam began a nonprofit called LoveYourBrain Foundation offering support to TBI survivors throughout the country by providing affordable yoga and meditation classes tailored to the needs of TBI survivors.

Laughter yoga

Laughter yoga is an alternative treatment for several diseases, mental disorders, emotional disturbances and trauma due to injury, fatal sickness or surgery.

Laughter yoga is a physical exercise and does not require any mental abilities. The therapy incorporates creativity, breathing techniques; group dynamics and eye contact make it easy for everyone to follow.

The benefits go beyond the feel good feeling that laughter provides. It also conditions the abdominal muscles, releases endorphins and reduces blood pressure.

Discuss positive experiences using any of the above therapies and share other quality of life therapy ideas not mentioned and your positive experiences using these therapies.

Discuss negative experiences using quality of life therapies and how you handled the experience. Is there anything that could have been done differently?

Prevention



Falls prevention

Most falls can be prevented. Some of the factors that can lead to a fall include.

- **Balance and gait.** Balance, flexibility and coordination may be lost through inactivity making it easier to fall.
- **Vision.** Changes may occur as individuals age, including less light reaching the retina causing contrasting edges, tripping hazards and obstacles become harder to see.
- **Medications.** Medications may cause a variety of side effects including dizziness, dehydration and other effects that may lead to increased falls.
- **Environment.** Modifications made to the environment can help reduce the chance of falls.
- **Chronic conditions.** Older adults often have chronic conditions that may result in lost function, inactivity, depression, pain or multiple medications that increase the risk of falling.

Identify possible modifications within the environment you are in that might reduce the chance of falls for an individual who may have poor vision and who may experience occasional dizziness from a medication they are taking.

Re-injury

Once an individual experiences a brain injury, there is a higher chance of a re-injury or second TBI. A re-injury might occur from a fall or other event. A second TBI is often worse than the first and every symptom of brain injury can drastically increase the risk of further injury.

Activities of Daily Living



Activities of Daily Living (ADL) are the tasks and roles a person routinely performs throughout their day. These tasks and roles might include personal care tasks (bathing, grooming, toileting and personal hygiene), mobility, meals, domestic tasks (laundry, house cleaning, home maintenance), shopping, bills and budgeting, taking medication, and other activities.

ADLs require a combination of physical and cognitive skills and often an individual who experiences TBI might have a number of deficits, which affects the ability to complete some of the activities.

As a caregiver, there will be some activities that will require more support and supervision from you.

Remember, it is important that each individual use their strengths and do as many of their ADLs as possible.

Some activities may require cueing. Cueing means to give a signal to begin a specific action or to give a clue or prompt for the individual to perform an activity. Cueing prompts a person to stop and think before acting. Cueing strategies can be shared amongst you and the others on the health care team.

The goal of progressive cueing is to gradually advance from being told what to do to being able to independently cue or remind oneself what to do. Learning how to self-cue increases independence.

You may help the individual by asking questions that help the person find a solution. Ask questions such as “what would you do to help yourself next time?”

You may also provide verbal and nonverbal cues. You might say, “Stop and think,” “what else could you do?” Or a nonverbal cue might be touching their arm to remind them to use that hand to complete a task. There are three types of cues:

Direct cue: a specific prompt. For example, “did you look in your calendar?”

Indirect cue: a general prompt. For example, “where could you find that information?”

Self-cue: “where could I find that information?”

Functional Independence

Functional Independence Measure (FIM) is an instrument that is a basic indicator of an individual’s ability, disability or limitations. It is used to track the changes in the functional ability of an individual during care. The FIM is comprised of 18 items, grouped into two subscales – motor and cognition.

The motor subscale includes:

- Eating
- Grooming
- Bathing
- Dressing, upper body
- Dressing, lower body
- Toileting
- Bladder management
- Transfers – bed/chair/wheelchair
- Transfers – toilet
- Transfers – bath/shower
- Walk/wheelchair
- Stairs

The cognition subscales includes:

- Comprehension
- Expression
- Social interaction
- Problem solving
- Memory

Each item is scored on a seven point ordinal scale ranging from a score of 1 (total assistance with helper) to 7 (complete independence with no helper.)

Lesson Summary

- It is impossible to predict all possible effects of damage because interactions within the brain and body are so complex and change over time.
- Focus on what has happened to the person rather than what is wrong with the person.
- Get to know each individual to learn what is important to the person as well as what is important for the person.
- Some individuals will have two or more conditions at one time and add to the complexity of support.
- Medications and quality of life therapies may or may not benefit individuals with brain injury. No two brain injuries are the same.

Checkpoint

Instructions: Read the scenario below and select the best answer from the options below.

Lena Buckner, an 81-year-old woman with a brain injury is experiencing sensitivity to sound. She has always loved listening to music and is finding it difficult to listen since her injury. How can you best support Lena to provide individualized quality care?

- A. Encourage Lena to limit exposure and participation in activities considered noisy.
- B. Encourage Lena to use or carry earplugs or headphones.
- C. Encourage Lena to add a fan, white noise or soothing music for background sound.
- D. All of the above.

Steven Jones, an 85-year-old who loves golfing and spending time in the outdoors is experiencing sensitivity to light since he experienced a brain injury. He is starting to feel depressed because he has been sitting inside avoiding the outdoors. How can you best support Steven to provide individualized quality care?

- A. Encourage Steven to stay indoors and find more activities for him to participate in.
- B. Encourage Steven to avoid eating orange colored fruits and vegetables.
- C. Encourage Steven to try tinted or polarized sunglasses or hats to minimize light while indoors/outdoors.
- D. All of the above.



Module 3: Behavior, Mood and Cognition Intervention and Resolution

The caregiver will demonstrate a sequence of steps to approach challenging behaviors to recognize and resolve changes in behavior, mood and cognition.

Module 3: Behavior, Mood and Cognition Intervention and Resolution

Objective

The caregiver will demonstrate a sequence of steps to approach challenging behaviors to recognize and resolve changes in behavior, mood and cognition.

Overview

Depending on what part or parts of a person's brain are injured, the individual may experience significant behavioral and emotional changes. The frontal lobe, for example helps govern personality and impulsivity. If damaged, there might be no "braking mechanism" for self-control. A person may find that they cannot control anger or aggression. The individual may also make inappropriate comments to others not realizing they are doing so. The opposite may also happen. Someone may develop "flat affect" where a personality may become muted or emotional.

Some of the most common behavioral and emotional problems individuals with TBI can experience include:

- Verbal outbursts
- Physical outburst
- Poor judgment
- Impulsive behavior
- Negativity
- Intolerance
- Apathy
- Egocentricity
- Inflexibility
- Risky behavior
- Lack of empathy
- Lack of motivation or initiative
- Depression or anxiety

This lesson gives you a general approach for approaching behaviors. As you work through each section, think about situations that you have been in and how you might apply this three-step approach in future situations.

Think about a time when your own behaviors were negative and how you felt at that time. Consider how others reacted or responded to your behaviors. Were there responses that made you feel better? Were there reactions that made you feel worse?



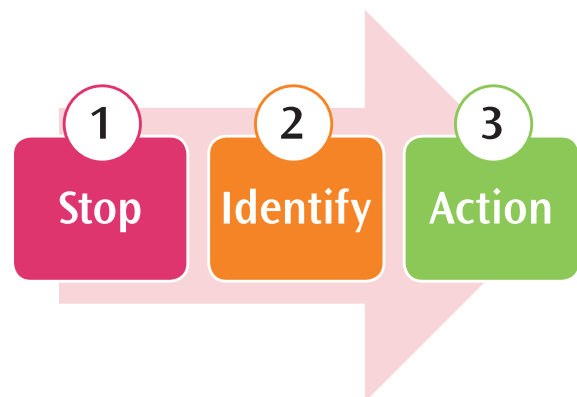
Exploring Behaviors

Individuals with a TBI use behaviors to communicate a personal need, feelings and emotions. There might be things going on with the person that may contribute to the behavior. In order to decide how to best respond to the behavior, stop and try to figure out what the person's behavior might be telling you. There is no one size fits all solution when dealing with behaviors. Every TBI is different and different people have different needs.

Strategy for Approaching Challenging Behaviors

While there are a number of strategies to work with behaviors, your primary role is to remain and appear calm and supportive and do not take the behaviors personally. Remember that the individual experiencing a TBI does not necessarily behave in a way to get attention or to be mean. They are expressing a need. You must learn the individual's history, habits, current needs and abilities. There is no right/wrong view of challenging behaviors.

To approach behaviors: Stop, identify and take action.



Step 1: Stop

When you are faced with an unexpected behavior, take a moment to stop yourself and take a pause from the situation. Make sure you are not reacting. Calm yourself and focus. Most challenging behaviors have a cause or a trigger. There is a reason for the behavior. Challenging

behavior is likely a reaction to something that set the behavior in motion. Having a reaction means that the individual might be unconsciously, emotionally and impulsively behaving without any thought to a situation or event. It is your job to respond. Responding is taking thoughtful action.

Responding rather than reacting to a challenging situation takes self-control and discipline. The best way to respond and not react is to stop before taking action unless someone is in immediate danger.

- Stop or pause even if only for a few seconds
- Calm yourself

Calming techniques

If you find yourself reacting instead of responding, there are many ways to get calm and focused. Find something that works for you.

- Take a few deep breaths.
- Count to ten.
- Detach yourself from the emotions of what is happening around you.
- Separate the behavior from the person.
- Recognize it is not about you.
- Repeat a positive phrase or affirmation to yourself such as “I am calm and relaxed in every situation,” “I remain calm and positive in difficult situations,” “I remain calm and in control under stress.”
- Get a clear picture in your mind of armor surrounding and protecting you from harm.
- Imagine a scene, person or experience that gives you a feeling of calm.

If you are still unable to calm and focus yourself, give yourself a brief time-out (if possible in your situation) or ask for help. It is better to walk away for a few minutes and collect yourself than to risk reacting and making the situation worse.

Karl Heintze is a man who experienced a brain injury at age 21 while riding a motorcycle. He is now 82-years-old and recently fell down a short flight of stairs and hit his head on the stairs. He is displaying some new behaviors recently that are not typical of his previous TBI. He has been seen by his doctor and has secondary TBI. Karl is currently yelling at you and calling you names.

Discuss how you can accomplish step one.

Step 2: Identify

After you complete step one, it is time to figure out what is happening. In step two, identify what caused or triggered the behavior. You should know the individual's routines, preferences and daily rhythms related to care

and life history. When you see a change that concerns you, remain emotionally available to the individual.

- Show genuine interest and concern.
- Realize that your own personal feelings of stress, personal worries and time pressures can add to any emotional tension the individual is experiencing.
- Listen to what the person is communicating through body language, words and the emotions behind their actions.

The individual might be expressing a need or desire or there might be a trigger that is physical, environmental and/or emotional. The individual may simply be frustrated that their brain and body cannot do what they want it to.

Expressing a need or desire

There are many reasons an individual may not be able to communicate needs and wants with words. The person with a TBI may not be able to:

- Speak.
- Process things quickly enough to explain what is happening or needed in the moment.
- Understand them due to the injury.
- Have strength to speak words. For example, he or she may be in too much physical and/or emotional pain.

Sometimes what you may see as a challenging behavior may be the only way the individual can tell you that they need or want something.

Physical, environmental and emotional triggers

The most common trigger is “flooding” where the individual has experienced sensory overload. The following are some additional common triggers to look for that may be causing the behavior.

Physical triggers such as

- Symptoms of the injury
- Symptoms of disease(s) or condition(s)
- Infection, such as Urinary Tract Infection (UTI)
- Pain
- Medication side effects or drug interactions. This is especially important when medications are added or stopped or there is a significant adjustment in dosage
- Dehydration
- Hunger or thirst
- Fatigue
- Recent injury
- Incontinence
- Constipation

- Unmet physical care needs such as needing to go to the bathroom
- Uncomfortable clothing
- Reaction to care being given

Environmental triggers such as

- Too much noise or people
- Intrusion into personal space
- Temperature (too hot or too cold)
- Something unfamiliar being added in the environment
- Something familiar being removed or moved
- Lack of privacy
- New environment or people
- Too bright or too dark
- Smells
- Full moon or sun setting
- Shift change

Emotional triggers such as

- Change in routine (especially if the individual feels no control over the change)
- Recent big changes or losses
- Difficulty with family, friends other care members
- Need to regain a sense of control
- Depression
- Boredom
- Past or current events, including holidays
- Anxiety
- Fear
- Loneliness
- Lack of intimacy
- Emotional state of other people

The perspective of the individual you are caring for is what is important when looking for possible triggers. What has triggered the individual's behavior can be very different from what would trigger you.

Other things to look for:

- What happened just before the behavior started?
- Were there other people involved when the behavior occurred?
- Where did it occur?
- What is happening in the person's living space?
- Is this a new behavior?
- Are there certain actions that make it worse?
- Is the individual trying to communicate a need or desire?

- Are there any patterns you can see? For example, is there a certain time of day, events such as shift changes, a particular caregiver or visitor, substances like drugs, alcohol, sugar or caffeine or after taking a certain medication that sets it off?

Karl Heintze is yelling at you and calling you names. You accomplished step one by stopping and taking a few deep breaths. Karl continues to yell at you, calling you names and saying that he is going to have you fired.

Discuss how you can accomplish step two.

Step 3: Action

Because there is no "one size fits all" formula to handle challenging behaviors, what works in one situation may not work in another and may not work in the same situation. What works with one individual may have the opposite result with another. The best way to deal with challenging behaviors is to adapt as you go to each unique individual and situation. This means that you must be:

- Constantly aware of signals the individual is giving off.
- Ready to adapt, walk away, soothe, distract or respectfully steer the individual away from what triggered the behavior.
- Willing to do something different if what you tried does not seem to be working.

Minimize or eliminate the trigger

If you have an idea what is causing the behavior, try to stop or minimize the trigger. If meeting an individual's need or request can minimize or eliminate the behavior, ask yourself the following questions:

- Does it hurt anyone to do it?
- Are you bothered because it:
 - Makes you change or adjust YOUR schedule?
 - Might look odd or unusual to others?
 - Requires you to "think outside the box?"
- Would be easier to do it the "regular" way or at a less busy or unusual time?
- Is the individual experiencing pain?

Adapt

Look for ways to adapt to the individual and their routine. This can include:

- Changing when or how the individual receives care.
- Breaking tasks down into smaller steps.
- Taking frequent breaks to allow the individual more time to do each step.
- Not doing certain tasks as frequently or doing them at a different time.

- Doing more prompting or cuing.
- Encouraging independence and choice in even the smallest ways.
- Using assistive devices to their fullest extent.

Common Pitfalls

Common pitfalls in taking action on challenging behaviors might include:

- Correcting behavior.
- Ignoring the behavior.
- Arguing with the person.
- Attempting to use reasoning to change the behavior.

Be aware and observant of subtle details. The answer for successfully navigating through challenging behaviors is often in the subtle details of who the individual is as a person.

- How do you know when the individual likes or does not like something?
- What types of things, situations, or people seem to make the individual frustrated, anxious or nervous, angry, etc?
- What pace of activity is comfortable for that individual?
- How do you know when it is too fast or too slow?
- How does the individual communicate (both verbally and with body language) what he/she wants?
- Is there anything you can learn about the individual's general personality that gives you an overall sense of the best way to work with them?
- Is there anything unique to the individual's culture that could be contributing to the challenging behavior?

When you get to know some of these more subtle things about an individual, you can watch for early warning signs of possible problems. Take action immediately to help the individual feel more calm and reassured (reduce or minimize the trigger, give space, calm, distract, reassure, etc.)

Give space

Ask yourself if giving the individual some space would be best. If it is safe, come back in five or ten minutes. This may give the individual time to calm down. Some quiet time may be all it takes to resolve the situation. Giving space can also mean staying with the individual and respecting his or her need for personal space. How much space does the individual appear to need around their physical body? Is the individual hypersensitive to touch? Movement? Claustrophobic? Is there a particular way you can approach the individual that seems less unsettling to them? Knowing the answers to these questions can help guide you in how to approach the individual any time, but especially when the individual is highly reactive.

Tips when approaching

Pay special attention how you approach individuals with a TBI. A sense that you are invading personal space is a common trigger of challenging behavior. Remember to:

- Knock. Ask permission to enter a personal space.
- Smile genuinely.
- Try to get the person's attention before you talk.
- Move slowly. Avoid sudden movements.
- Identify yourself and why you are there.
- Address the individual by the preferred name.
- Spend a few minutes talking with the individual before providing care. This gives you time to see how the individual is doing and gauge if it is safe to proceed with care.
- Explain what you are doing and confirm that they heard you accurately.

Soothe and comfort

- Slow down your own movements and energy.
- Try not to show any anxiety or other intense emotions. They will likely increase the reactions from the individual.
- Validate the person's feelings.
- Speak slowly, softly with a low pitch and in a reassuring tone. Make sure the individual can hear you if he or she has trouble hearing.
- Offer choices you know comfort that individual (warm blanket, rocking chair, quiet music, a cup of tea, turning on a favorite show, a favorite object, holding a pet).
- Reduce distractions or loud background noises as much as possible. Examples might be turning down the TV, asking others in the room to step out, or turning down the lights. Ask the individuals permission before doing any of these things.
- Play relaxation or anti-anxiety music or meditations.
- If touching might be comforting, offer physical comfort such as lightly stroking the individual's hand, giving a hug or a back rub. The appropriateness of comforting touch depends on the individual and policies where you work. If offering comforting touch is allowed, ask the individual's permission first. Make sure you know preferences when it comes to touch and back off immediately if it further upsets the person.

As a general rule, remember that your body language is your best communication tool. This means that it is critical that:

- Your posture, facial expressions and stance are relaxed and open.
- Your tone is respectful and calm.
- You move slowly.

- You stop what you are doing and focus on the individual.
- Your body language matches the words you say to the individual.

Reassure

- Listen! Let the individual talk about their feelings. Do not ask a lot of questions at first. Let the individual get some of the excess emotions out. Listening helps make sure the individual knows that he/she has been “heard” by you. Listen to both words and body language.
- Be understanding and sympathetic. The individual will be more likely to respond favorably if you sound sympathetic rather than insincere, annoyed, frustrated or angry.
- Maintain clear boundaries if you are treated with disrespect or threatened.
- This is not the time to have a talk about the behavior. Wait until later when the situation is calmer to work through any boundary issues or concerns.

Distract or redirect

- Distract the individual by offering choices such as a calming or favorite activity such as a walk, snack or beverage.
- Change the conversation to something positive that may redirect the person.
- Encourage the person to take several deep breaths.
- Reinforce positive behaviors.

Encourage

- Listen.
- Use praise liberally while remaining mindful that the individual is an adult. (Be careful that the praise does not become child-like)
- Reinforce positive behavior no matter how small.
- Encourage keeping happy reminders, such as family pictures or treasured keepsakes in plain view.
- Encourage the individuals to engage in healthy behaviors in diet, exercise and socializing with others.

Protect and support others being impacted by the behavior

It can be upsetting for others to see or be part of the challenging behavior. Remember to stay aware of others in the area. Take action to support and protect others if they are impacted.

Get help

Know your limits. If you need help, get it. Especially when medical or other emergency help is needed. Know what your policy is on involving other individuals such as medical personnel, other team members, family, friends or guardians.

Speak up immediately if you ever feel you are at your own breaking point or limit when dealing with an individual who is exhibiting challenging behavior.

Self-care

As a caregiver, you need to replenish your emotional reserves after handling stressful behaviors. This requires good self-care. Take time to manage your feelings.

Karl Heintze is yelling at you and calling you names. You accomplished step one by stopping and taking a few deep breaths. When Karl continued to yell at you, calling you names and saying that he is going to have you fired, you identified what caused or triggered the behavior.

Discuss how you can accomplish step three.

Prevent or minimize challenging behaviors

Once the heat of the moment has passed, you may have more time to reflect on what triggered the challenging behavior. This information helps you take steps to avoid these situations from happening again. With more time to reflect, you may see additional patterns or concerns.

Document and report

You may have important information to share with other team members. Others on your team need to understand and learn from what you observed, what actions you took and what did and did not work.

There will be policies and procedures for documenting and reporting challenging situations that you must follow. Objectively writing down what happened and what actions you took gives everyone a record. This record will help make sure you do not forget even small details, that when reviewed again, might reveal important information.



Handout: Changes and TBI

Changes in behavior	Interventions
<p>Changes in sexual behaviors</p> <p>Many people with TBI change how they act during intimate moments. Some individuals with moderate to severe TBI may sometimes act in sexually inappropriate ways. These behaviors can often be managed over time.</p> <p>This might look like hypersexuality, hyposexuality or lack of interest in sex, discomfort with intimacy, trying to kiss or touch strangers, making suggestive or flirtation comments to or about others, disrobing or engaging in masturbation in front of others.</p>	<p>Develop a stop and think signal, use redirection, talk to the individual about what are and are not acceptable ways to act in public, talk about having sexual feelings is normal, find healthy ways for the individual to express sexual needs.</p>
<p>Decreased ability to initiate conversation or activity</p> <p>Sometimes an individual with TBI will seem to have lost interest in activities they once enjoyed. The individual may remain in bed until encouraged to get up, spend a lot of the day sitting around not actively engaged in activities, not speaking unless spoken to, has problems completing tasks without a lot of supervision and agreeing to do something but then not following through.</p>	<p>Set up a regular schedule for the individual to follow. The goal is to learn a routine so well that it becomes automatic. Post a schedule. Work with the individual to develop a list of goals or tasks to be completed and encourage the individual to become involved. Having purpose along with structure is helpful.</p>
<p>Faulty or poor judgment</p> <p>Sometimes it is hard for a person with TBI to analyze a situation and understand what could happen. The individual may make inappropriate or harmful decisions, experience difficulty with reasoning and experience ineffective problem solving.</p>	<p>Help the individual to use effective problem-solving skills:</p> <ul style="list-style-type: none"> • Identify the problem • Brainstorm possible solutions • Evaluate the alternatives • Choose a solution • Role play to prepare for situations • Have the individual try the solution • Evaluate the solution
<p>Frustration, increased anger/aggressiveness</p> <p>The individual may have a strong reaction to minor annoyances or frustrations, a general lack of patience, low tolerance for change, unexpected outbursts of anger, increased irritability, verbal or physical demonstrations of anger, increased anger when tired or in new situations and during high levels of stress.</p>	<p>Develop a plan to manage frustration or anger. This might mean taking a walk or going to another room and turning on the television. This might also be a good signal that the individual might need some alone time for a while.</p> <p>Remain calm and encourage the individual to recognize when he/she is becoming angry or frustrated.</p> <p>Reinforce all efforts to use effective anger management strategies.</p> <p>Try to avoid surprises. People with TBI do better when they are prepared and can anticipate a change in plans.</p>

Changes in behavior	Interventions
<p>Impaired self-awareness about how TBI impacts him/herself and others The TBI survivor may not be aware of how the injury has affected themselves and how it affects others. Self-awareness usually improves with time and feedback from others.</p> <p>The individual may underestimate the problem areas related to TBI, may not understand why rehabilitation therapies are needed, might not follow the recommendations of the healthcare team, have unrealistic expectations about future plans or abilities and may have inaccurate self-perception or self-image.</p>	<p>You can help this by being supportive with problem solving techniques, giving realistic and supportive feedback, set realistic goals and develop plans to take steps toward larger goals and use a memory notebook to track progress and setbacks.</p>
<p>Impulsivity or difficulties in self-control The individual may react before thinking, saying whatever comes to mind without thinking about how it might affect self or someone else, acting without thinking about consequences, making inappropriate comments to or about others.</p>	<p>Use redirection (suggest a different activity or topic), develop a special stop and think signal that you can use to alert the individual when they are doing or saying something inappropriate, suggest the individual stop, think, slow down and consider options. Avoid comparing past and present behaviors.</p>
<p>Less effective social skills Social skills are all of the things we say and do in order to fit in, get along with others and read and understand the people and situations around us. This includes thinking of topics for conversation, listening to the other person without interruption, keeping a conversation going, reading facial and verbal cues.</p> <p>The individual may have a lack of awareness of personal space and boundaries, reduced sensitivity for feelings of others, possible disregard for accepted standards of conduct at home or out in public, use of vulgar language or behavior.</p>	<p>Respond calmly, role play or rehearse responses to social situations, use an agreed-upon signal to let the individual know that he/she may be saying something inappropriate, use redirection, praise and reinforce appropriate behavior.</p>
<p>Repetitive behaviors (perseveration) Perseveration means being stuck on one idea or one behavior and repeating it. Injury to the frontal lobe of the brain is the cause. The individual may write the same letters or words or repeat the same word or phrase over and over, repeating physical movements or tasks and getting stuck on one topic or theme.</p>	<p>Use redirection (change topic or focus of interest to something else), try to engage the individual in a physical task if the individual is verbally stuck on a topic. Try engaging the person in a conversation or thinking task if he/she is stuck on a task.</p>

Changes in mood	Interventions
<p>Changes in self-esteem</p> <p>A person's view of himself or herself can be negatively impacted by a TBI, including feelings of low self-esteem.</p> <p>The individual might say things like "I am worthless" or "I'll never be normal again". The individual might be less interested in their personal appearance and withdraw socially.</p>	<p>You can help by encouraging the individual to express their feelings or try to redirect to think positive thoughts. Encourage the individual to spend time with others and take part in independent activities.</p>
<p>Depression</p> <p>Many people with TBI become depressed from the physical changes in the brain and the emotional reactions to it. Sometimes it is hard to tell the difference between symptoms of depression and the effects of TBI.</p> <p>The individual may be persistently sad, anxious or have empty feelings, feelings of hopelessness or guilt, worthlessness, irritability, anger and restlessness. The individual may also have a loss of interest in activities and hobbies that were once pleasurable, fatigue and decreased energy, problems concentrating and in some cases thoughts of suicide or suicide attempts.</p>	<p>You can help by offering emotional support, providing understanding, patience and encouragement. Talk to the individual and listen carefully. Acknowledge feelings. You should also consider taking a mental health course to help you navigate more common concerns such as depression and anxiety.</p>
<p>Increased anxiety</p> <p>People with TBI often become anxious. Anxiety sometimes goes hand in hand with depression.</p> <p>The individual may have constant physical tension, excessive worry, racing thoughts, feeling jumpy, irritable or restless. The individual may experience a racing heart, dry mouth, excess sweating, shakiness or feeling short of breath or having feelings of panic or a sense that something bad is going to happen.</p>	<p>You can help by helping the individual to use problem-solving techniques to address any problems that he or she may be worried about. Suggest writing things down in a journal. Use redirection such as changing the topic or focus of interest. You should also consider taking a mental health course to help you navigate more common concerns such as depression and anxiety.</p>
<p>Mood swings (emotional lability)</p> <p>People experiencing TBI often experience mood swings making it difficult to participate in social situations.</p> <p>The individual may laugh one minute and feel sad or cry the next. The individual may have emotional responses that do not fit the situation such as crying when others are laughing.</p>	<p>You can help by reassuring the individual that you understand and remain nonjudgmental. Use redirection (change the topic or focus of interest to something else).</p>

Changes in cognition	Interventions
<p>Attention and concentration</p> <p>The individual may be unable to focus, pay attention or perform more than one task at a time. This can cause restlessness and being easily distracted. It can cause difficulty in finishing more than one task at a time. It can also cause problems in having long conversations or sitting still for long periods.</p>	<p>You can help by decreasing distractions for the individual and encourage the individual to focus on one task at a time. Encourage the individual to practice attention skills by gradually making tasks harder or increasing distractions in the environment over time. You can also encourage the individual to take breaks when tired.</p>
<p>Processing and understanding information</p> <p>After a brain injury, individuals may experience problems with a slowing of processing and understanding information. The individual may take longer to understand what others are saying and take more time to understand written or verbal information. The individual may also be slower to react and may be slower to carry out physical tasks including routine activities.</p>	<p>You can help by encouraging the individual to focus his or her full attention on one task while decreasing distractions. Give the individual more time to think and process before moving on. Encourage the individual to repeat what they heard to make sure they understand it correctly.</p>
<p>Language and communication</p> <p>An individual with a brain injury may have communication problems, which increases difficulty understanding and expressing information. The individual may have difficulty thinking of the right word or have difficulty starting or following conversations or understanding what others are saying. The individual may ramble or get off topic easily. The individual may have difficulty with expressing thoughts in an organized manner or have trouble communicating thoughts and feelings using non-verbal communication.</p>	<p>You can help by working with a speech therapist on areas that are identified as needing improvement after an injury. You can also use kind words and a gentle tone of voice, ensuring that you do not talk down to the person. Confirm that the individual is understanding what you are communicating and do not speak too fast or give too much information at once. Encourage the individual to limit conversations to one person at a time.</p>
<p>Learning and remembering new information</p> <p>Individuals with a brain injury may have trouble learning and remembering new information and events. The individuals may also have trouble remembering events that happened several weeks or months before the injury although this often comes back over time. Events that happened long ago usually are remembered. There may be problems remembering entire events or conversations and the individual's mind may try to fill in the gaps of missing information and recall information that did not actually happen.</p>	<p>You can help the individual by encouraging a structured routine of daily tasks and activities. Encourage the individual to stay organized and have a set location to keep things. Encourage use of memory aids such as calendars, notebooks, daily schedules, daily task lists and cue cards. Encourage rest and ways to reduce anxiety.</p>

Changes in mood	Interventions
<p>Planning and organization</p> <p>Individuals may have difficulty planning their day and scheduling appointments or may have difficulty with tasks that require multiple steps done in a specific order.</p>	<p>You can help the individual by encouraging them to make lists, thinking about the steps needed to complete an activity and break down activities into smaller steps.</p>
<p>Reasoning, problem-solving and judgment</p> <p>Individuals with TBI may have difficulty recognizing when there is a problem and may have trouble analyzing information. When solving problems, individuals may have difficulty deciding on a best solution and may make quick decisions without thinking about consequences.</p>	<p>You Encourage the individual to work with a speech therapist or psychologist can help the individual by: ho is experienced in cognitive rehabilitation and who can teach an organized approach for daily problem solving and support the individual in their rehabilitation.</p>
<p>Inappropriate, embarrassing or impulsive behavior</p> <p>Individuals with brain injury may lack self-control and self-awareness and as a result, they may behave inappropriately or impulsively in social situations. The individual may deny they have cognitive problems even if these are obvious to others, may say hurtful or insensitive things, act out of place or behave in inconsiderate ways. The individual may also lack awareness of social boundaries and others' feelings such as being too personal with people they do not know well or not realizing when they have made someone uncomfortable.</p>	<p>You can help the individual by giving realistic, supportive feedback as you observe inappropriate behavior. You can provide clear expectations for desirable behavior before events or activities. Establish verbal and non-verbal cues to signal the individual to stop and think.</p>

De-escalation



In any situation, the only thing you have complete control over is yourself. Caregiving is a profession that provides care for individuals who will experience crisis. People who experience a traumatic brain injury may be combative as they reorient to the world around them and become aware of the changes they experience after injury. Individuals will respond to stress in different ways although a predictable pattern recognized in five phases: triggering event, escalation, crisis, recovery and post-crisis depression. This is known as the assault cycle. In the escalation phase, the individual will experience increasing levels of agitation. De-escalation techniques are used during this phase to try to help the individual return to baseline (their normal levels of behavior). Successful de-escalation begins with you and your attitude, beliefs and actions.

Strategies

Preventing Crisis:

- Monitor body posture, tone of voice, content of speech and use of gestures for signs of increasing agitation.
- Increase rest time for the individual, especially during times of day when there is a pattern of increased agitation.
- Keep the environment simple.
- Keep instructions simple.
- Give productive and positive feedback.
- Set goals with the individual that gives the individual an opportunity for small successes in their progress.
- Stay calm.
- Redirect the individual to a different activity, space or topic when it appears that they are showing signs of increased agitation.
- Vary type of activities.

Interventions:

- Active listening incorporates a variety of listening skills such as paraphrasing, clarifying and perception checking.
- Orientation involves awareness to time, place and person.
- Setting limits can be useful for individuals who are trying to intimidate by threatening behavior.
- Redirecting the individual to another task or activity may interrupt the escalation phase.
- Withdrawal of attention may be effective with manipulative types of behavior.
- Give the individual a time out.
- Know when not to push the individual.

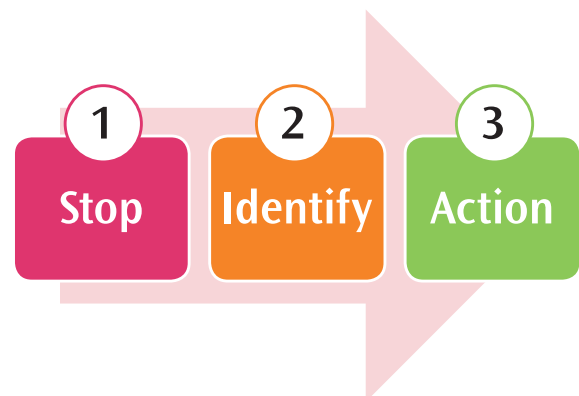
Discuss examples of behaviors that would require de-escalation and ways that you can support the individual.

Specific Behavioral Challenges and Steps

The Washington State Department of Social & Health Services Aging and Long-Term Support Administration (DSHS/ALISA) conducted research to identify the most common reasons for an individual living in one setting (Assisted Living Facility (ALF), Adult Family Home (AFH)) transferring to a new setting. The behaviors listed in this section are the highest rated reasons for moves. Becoming familiar with these behavioral challenges and steps to take to address them will help give you better tools to be prepared for these challenges to provide better care for the individual and yourself.

Remember our three step process to handle challenging behaviors. You can refer back to those steps on pages 29-31 as you encounter the following behaviors.

1. Stop and remain calm.
2. Identify what is going on.
3. Take action.



Anger

An individual who has experienced a TBI may feel a loss of independence, fatigue, overstimulation or cognitive problems, which may lead to feelings of frustration and anger.

The individual may experience:

- A strong reaction to minor annoyances or sources of frustration
- Increased irritability
- Increased tendency towards anger
- Lack of patience
- Low tolerance for change
- Unexpected outbursts of anger
- Verbal or physical demonstrations of anger
- All or a combination of the above

Stop and remain calm.

Identify what is going on.

- What is triggering the behavior?
- Are the surroundings not conducive to what you want to accomplish?
- Are people not listening?
- Is there caregiver awareness?
- Is there a pattern?
- Does the individual need a medication adjustment?

Take action.

- Ask yourself if the behavior is harmful. If it is not harmful, can you let it go?
- Do not let the behavior get out of control.
- Communicate calmly with the individual.
- Can you reduce or modify the triggers?
- Is the individual having difficulty with something?
- Develop a plan to manage the frustration and anger.
- Prepare to prevent future behaviors.
- Walk away and let the individual calm down, then communicate.
- Get help as needed.
- Call 911 if needed.

Margaret Crowther, a 68-year-old TBI survivor becomes irritable whenever the blender is used and she has a strong reaction of frustration with her environment when someone wears perfume or cologne. Today, Margaret is showing signs of anger and irritability. Using the three-step process, discuss how you might support Margaret.

Step 1:

Step 2:

Step 3:

Combative During Personal Care

Combative behavior often describes physical aggression such as hitting, pushing, kicking, spitting and grabbing.

The individual may experience:

- Hitting
- Shoving
- Scratching
- Biting
- Pinching
- Spitting

Stop and remain calm.

Identify what is going on.

- The individual may be experiencing pain.
- Is there a trauma response? Why?
- Is the behavior a problem?
- Is the individual embarrassed?
- Is there something the individual does not like?

Take action.

- Stop doing the task.
- Ask questions.
- Create a care plan to limit the behavior in the future.
- Identify what is important to them and for them.
- Recognize when you are over your head and ask for help.
- Listen to the individual.
- Recognize that people are allowed to change their mind.
- Explain what you are doing.
- Allow someone else to perform the task.
- Ask the individual to do all or part of the task.
- Give the individual something to spit in (for spitting).

Randy Le, a 51-year-old TBI survivor is refusing to shower. You try to talk Randy through the process and still he does not want to shower. He pushes you away. This is a new behavior for him. Using the three-step process, discuss how you might support Randy.

Step 1:

Step 2:

Step 3:

Crying and Tearfulness

Mood swings and emotional lability are often caused by damage to the part of the brain that controls emotions and behavior. In some cases, the brain injury can cause sudden episodes of crying or laughing and may have no relationship to how the person feels.

The individual may experience:

- Explained or unexplained crying (or laughing) out of context.

Stop and remain calm.

Identify what is going on.

- Why is the individual crying?
- How are they really feeling?
- Did something happen?

Take action.

- Avoid reacting emotionally yourself.
- Find out why they are crying.
- Take the individual to a quiet area and try to calm so they can regain control of their emotions.
- Give validation of feelings and give the person a chance to talk about feelings.
- Provide feedback gently and supportively after the individual regains control.
- Gently redirect attention to a different topic or activity.
- Wait it out and come back later.

Gregory Coady, a 62-year-old man who survived a TBI in his temporal lobe and will occasionally begin crying and you are having trouble finding a reason for his crying and tearfulness. You notice Gregory participating in an activity and says he wants to continue to participate. Using the three-step process, how might you support Gregory?

Step 1:

Step 2:

Step 3:

Disrobes in Public

Public disrobing targets dress behavior that is contrary to local community laws, norms and individual's usual behavior. The individual is unaware that this is inappropriate.

Impairments in inhibition may occur when frontal lobe damage is present.

The individual may experience a variety of inhibitions including:

- Undoing buttons on blouse so that breasts are exposed
- Taking off pants
- Disrobing in public places

Stop and remain calm.

Identify what is going on.

- Find out if the clothes are uncomfortable.
- Is the individual too hot?
- Does the individual prefer other clothing?

Take action.

- Maintain dignity of the individual. (Get a blanket, redirect, etc.)
- Give reminders of appropriate and not appropriate behaviors.
- Be prepared if this is a pattern.
- Create a plan on what to do when an individual is going to come out without clothes.
- Find clothes that are more comfortable.
- Make the individual part of the problem solving then have their buy in on the situation.
- Let the individual select different clothes.
- Use creative thinking.

Penni Rouse, a 64-year-old woman with a TBI worked for most of her life as a bookkeeper at a large department store. She always dressed professionally in skirt, blouse, stockings and high heel shoes. She was often complimented on her attire. Recently, Penni will often pull at her clothes and start to remove her pants in the dining room. How might you support Penni using the three-step process?

Step 1:

Step 2:

Step 3:

Eats Non-Edible Substances/Objects

Some individuals may eat non-edible, non-nutritive substances or objects such as plants or paper.

The individual may experience:

- Eating substances or objects that are not considered edible such as clay or soil, paint or metal objects.

Stop and remain calm.

Identify what is going on.

- What is going on?
- Does the person have Pica?
- Is there a loss of sense of taste?
- What are the implications of this?
- Is there an iron or other vitamin deficiency?
- How is the person's nutrition and nutrient intake in general?
- Are there nutrient deficiencies?
- Is there another mental disorder present such as autism, schizophrenia or obsessive-compulsive disorder that may experience pica?
- Does the item look like a food item?

Take action.

- Redirect the individual to food.
- Remind the individual of the consequences of eating non-edible objects.
- Remind the individual what food is and what is appropriate to eat.
- Lock up cleaning supplies.
- Offer more spice to the person's food.
- Seek guidance from a medical professional regarding any deficiencies.

Pica is the persistent eating of substances such as dirt or paint that have no nutritional value. If pica is suspected, a medical evaluation is important to assess for possible anemia, intestinal blockages or potential toxicity from ingested substances.

Dustin Esposito, age 75, has experienced obsessive-compulsive disorder for his entire life. Later in life, Dustin was diagnosed with pica and used nutrition to manage anemia. Recently, Dustin fell and sustained a second TBI and is currently recovering, however you have found him eating dirt from the plant outside his room two days in a row. How might you support Dustin using the three-step process?

Step 1:

Step 2:

Step 3:

Hallucinations and Delusions

Although hallucinations and delusions are not real, the experience and feelings are real to the person and can be frightening. While you may not be able to control the hallucination or delusion, you can use your problem solving skills to help come up with a response.

The individual might experience:

- Seeing people or objects that are not there.
- Hearing voices or noises that do not exist.
- Being overly suspicious or have a distorted idea about what is actually happening.

Stop and remain calm.

Identify what is going on.

- Assess and evaluate the situation – is the hallucination or delusion a problem for you or for the individual?
- Is it upsetting to the individual? Is it placing the person in danger? Is the person frightened?
- Investigate for any misperceptions of the environment.
- Is the individual perseverating? Perseverating is being stuck on an idea.
- Is there a trigger?
- Is there change happening?
- Is there a medication that is causing the hallucinations or delusions?
- Is there stress?

Take action.

- Make sure the individual is safe.
- Move to a location they will not harm themselves.
- Do not argue with the individual.
- Find out what they are seeing.
- Report anything new.
- Do not validate what they are saying.
- Offer reassurance
- Check glasses, hearing devices and medications.
- Call 911 if there is danger.

Elizabeth Martini is 69 years old and is formerly a construction manager who survived a TBI falling from a second floor of a building. Elizabeth has been increasingly confused and hallucinating today. She seems to be perseverating (stuck on the idea) that she needs a dose of her medication and it is the root of all of her problems. You know that there are some changes in care for her lately causing her stress and she is on a new medication. How might you support Elizabeth using the three-step process?

Step 1:

Step 2:

Step 3:

Inappropriate Toileting/Menses Activity

Cognitive and physical problems may occur from brain injury that cause a person to have difficulty with using the toilet.

The individual might experience:

- Smearing or throwing feces
- Urinating in inappropriate places
- Defecating in inappropriate places
- Inappropriate menses activity

Stop and remain calm.

Identify what is going on.

- A lack of awareness or lack of sensation of a full bowel or bladder that needs to be emptied.
- A decreased desire to urinate or defecate in an acceptable manner.
- A need to relearn social expectations.
- Urinating outdoors may be a behavior learned in childhood.
- Is the individual thinking they are doing the right thing, just not in the right place?
- Can they see the toilet?

Take action.

- Help the individual change soiled clothes.
- Regularly help to use the toilet or latrine.
- Develop a schedule for using the toilet.
- Encourage cleaning of genitals and hands after using the toilet if able.
- Use supports when sitting down and getting up from toilet.
- Provide pictures of the bathroom for recognition.
- Anticipate times and needs so you can assist them in maintaining their dignity so we do not overact.
- *Remember that putting clothing on backwards to prevent toileting issues is considered a restraint and is not allowed.

You walk into the room and find Joseph Trujillo, a 73-year-old brain injury survivor, urinating in the floor vent. Joseph speaks English as his second language and his English is limited. How can you support Joseph using the three-step process?

Step 1:

Step 2:

Step 3:

Injures Self

Includes both lethally motivated suicidal behaviors (intentional, self-inflicted attempt to kill oneself), and behavior inflicting intentional self-injury without suicide intent (e.g., self-mutilation).

An individual who has a TBI may have prior history of deliberate self-harm and may be responsible for increased suicide rates.

The individual might experience:

- Skin cutting
- Head banging or hitting
- Burning
- Excessive scratching
- Punching self or objects
- Drinking something harmful
- Breaking bones
- Self-choking
- Poking self in eyes

Stop and remain calm.

Identify what is going on.

- Is the person self-inflicting damage with expectation of physical harm?
- Does the person have suicidal intent?
- Did something just happen in the environment that might cause negative feelings or thoughts?
- Is there another mental, developmental or other medical condition?

Take action.

- Your responsibility is to protect the individual, even from themselves.
- Seek outside professional help.
- Report for outside medical and psychiatric help.

Sheila Arend, a 28-year-old TBI survivor has a history of picking her skin until she draws blood. Since her car accident and is currently immobile, the picking has increased according to her family. Today when you assist Sheila with dressing, you notice that her skin on her inner arm is red and bleeding. How can you support Sheila using the three-step process?

Step 1:

Step 2:

Step 3:

Intimidating/Threatening

Intimidating is when someone behaves in a way to frighten or make you fearful. Threatening is expressing a hostile or deliberately frightening behavior. Emotional problems as well as increased aggression and anger may occur after a brain injury.

The individual might experience:

- Attempting to force or deter someone else using threatening gestures
- Threatening stance with no physical contact
- Shouting or screaming angrily
- Personal insults
- Curses directed at someone else
- Using foul language in anger
- Kicking the wall
- Throwing furniture
- Showing an intention to cause bodily harm
- Cause someone to feel vulnerable or at risk

Stop and remain calm.

Identify what is going on.

- Does the individual recognize that they are intimidating?
- What happened just before the behavior?
- Is there a trigger?
- Is the individual upset about something?
- Is the individual in pain?

Take action.

- Your responsibility is to protect the person being intimidated or threatened.
- Having a TBI does not give a person the right to intimidate or threaten others.
- Find a way to structure it in the care plan – for example, keep individuals separated if there is a pattern.
- Set clear boundaries.
- Consider using strategies that worked in the past.
- Say, “I notice you are escalating...”

John Cano, age 73, fell two weeks ago when he was getting out of bed too quickly. His doctor diagnosed John with a concussion. John is experiencing extreme sensitivity to light and severe migraines. You enter the dining room and John is speaking loudly to a man named Todd saying “Everyone hates you, just so you know!” You can see that Todd is distressed. How can you support John and Todd using the three-step process?

Step 1:

Step 2:

Step 3:

Mood Swings

Rapid, abrupt shifts in emotions.

Mood swings and emotional liability often caused by damage to the part of the brain that controls emotions and behavior. Moods swings refer to rapid changes in mood. Mood might fluctuate from irritability to extreme sadness to angry outbursts.

The individual might experience:

- Periods of tearfulness alternating with laughter with or without a reason.
- Noticeable change in mood or emotional state.
- Emotional response for no reason.
- Emotional expression that does not match the situation.

Stop and remain calm.

Identify what is going on.

- How recent is the brain injury?
- Could this be a result of medication?
- Was there something that triggered the response?
- What happened just before the mood swing?
- Has anything changed recently that might cause an emotional response?

Take action.

- Take the person to a quiet area to help regain control of emotions.
- Acknowledge feelings and give the person a chance to talk about their feelings.
- Provide feedback gently and supportively after the person gains control.
- Gently redirect attention to a different topic or activity.
- Reduce stress.

Holly Jameson, is a 45 year old survivor of domestic violence resulting in a TBI. She has had the TBI for about a month. Her mood is often unpredictable: laughing, crying, angry. You notice that she is crying again when just a moment ago she was laughing. How might you support Holly using the three-step process?

Step 1:

Step 2:

Step 3:

Repetitive Anxious Complaints or Questions

Non-health related.

Perseveration is the persistent repetition of a response – a word, a phrase or a gesture.

The individual might experience:

- Persistently seeks attention or reassurance regarding schedules, meals, laundry, clothing, relationship issues, etc.
- Respond to a question then repeat the answer repeatedly – even after the person who has asked the question has left the room.
- Asks the same question repeatedly.
- Complains repeatedly.

Stop and remain calm.

Identify what is going on.

- Is the individual perseverating?
- Is the individual trying to remember something by repeating it?
- Is there validity to complaints and questions?

Take action.

- Be repetitive with them.
- Reminders on a communication board.
- Consistency and scheduling. Stick to it.
- Empower the person for daily activities.
- Not all strategies work for all, tailor the strategies to the individual.
- Be a cheerleader when it works.

Todd Ballard, age 78 has had a TBI since he was in his late 50s from a motorcycle accident. He also has anxiety. He often perseverates when his anxiety is heightened. How can you use the three-step process to support Todd the next time you find him perseverating?

Step 1:

Step 2:

Step 3:

Repetitive Physical Movements and Pacing

Perseveration means getting stuck on one idea or one behavior and repeating it. Often the frontal lobe is the cause.

The individual might experience:

- Repeating physical movements or tasks
- Hand wringing
- Fidgeting
- Restlessness
- Picking at body and clothing

Stop and remain calm.

Identify what is going on.

- Did something trigger the behavior?
- Is it anxiety?

Take action.

- Use redirection to a new activity.
- Try engaging the person in a conversation or thinking task if they are physically stuck on a task.
- If pacing, make the environment safe. Create rest areas to encourage rest stops when they can.
- Get outside professional help.
- Report for outside medication and/or psychiatric help.

Curtis Welsh, 76, was in a ski accident and survived a brain injury to the frontal lobe of his brain. He often paces up and down the hall touching each doorknob he passes. He is looking tired. How can you support Curtis using the three-step process?

Step 1:

Step 2:

Step 3:

Resistive to Care with Words and Gestures

Individuals with a TBI may be resistive to care with words and gestures. The brain oversees everything we do including communication and how we behave.

The individual might experience:

- Communicates with words such as “get away from me,” “leave me alone,” “don’t touch me” when receiving care.
- Communicates with actions such as pushing, hitting and kicking when receiving care.
- Resists taking medications or injections.
- Resists assistance with activities of daily living, help with eating or treatments.

Stop and remain calm.

Identify what is going on.

- Did something trigger the behavior?
- Is the individual aware of what is happening around them?
- Are you giving adequate information for the individual to know what is happening during care?

Take action.

- Provide visual and verbal cues and information through providing care for the individual.
- Allow the individual to do as much of the process as they are able, building on their strengths.
- Offer choices.
- Use a person-centered approach.

Marguerite Mayes, 55, was physically active before her brain injury – running marathons and climbing mountains. She is unable to be physically active the way she used to be before her injury and often has difficulty with personal care. She yells at you and pulls her arm away from you when you try to assist her today with care. How might you support Marguerite using the three-step process?

Step 1:

Step 2:

Step 3:

Rummages Through or Takes Belongings of Others

Rummaging is a way of searching through items or places such as cabinets, drawers, closets, the refrigerator and other places that things are stored. There may be times that the individual is behaving this way for a reason such as searching for something specific like an item or food. Try to understand what is causing the behavior.

The individual might experience:

- Searching through cabinets, drawers, closets or other places that things are stored.
- Looking for something specifically.
- Can or cannot communicate what he/she is looking for.

Stop and remain calm.

Identify what is going on.

- Did the individual lose something?
- Is he/she looking for something?
- Is he/she hungry?

Take action.

- Help the individual find what they are looking for.
- Lock up dangerous or toxic products or place them out of sight and reach.
- Remove spoiled food from the refrigerator and cabinets.
- Remove valuable items that could be misplaced or hidden.
- Provide activities for the individual to keep them engaged and active.

Robert Zamora, 79, has a traumatic brain injury and is showing symptoms of dementia. You found out that he is rummaging through other people's belongings and taking items, claiming that they are his. How might you support Robert using the three-step process?

Step 1:

Step 2:

Step 3:

Seeks Vulnerable Sexual Partner or Sexual Acting out

Changes in sexual functioning are common after TBI. Some changes are directly related to damage to the brain and other changes are related to physical problems or changes in thinking or relationships.

The individual might experience:

- Exposing genitals to others
- Disrobe in public
- Engaging in masturbation in front of others
- Touching genital areas
- Touching non-genital areas
- Looking for opportunities to watch others undressing
- Forcible grabbing of another person
- Attempting to undress another person
- Attempting non-consenting intercourse with another person

Stop and remain calm.

Identify what is going on.

- Did something happen to trigger the behavior?
- Is the individual seeking sensory stimulation because it feels good to them?
- Is the individual attention seeking?

Take action.

- Use redirection – try to change the topic or focus of interest
- Create a behavior plan
- Develop a stop and think signal that the behavior is inappropriate
- Find ways for the individual to express sexual needs in appropriate ways

You walk into the living room and Steve Piper, age 46, is sitting on the couch masturbating. How might you deal with Steve's behavior using the three-step process?

Step 1:

Step 2:

Step 3:

Spitting

Spits inappropriately e.g. on the floor, or at others.

See combative during personal care on page 41.

Unrealistic Fears or Suspicions

Expresses fear of being abandoned, left alone, or being with others. There is no basis for this fear or belief.

The individual might experience:

- Expressing fear of being abandoned, left alone or being with others.
- The individual is unwilling to be left alone.
- May follow you or other significant individuals of importance to them, unwilling to let these individuals out of their sight.

Stop and remain calm.

Identify what is going on.

- Is the individual expressing a need?
- Did something happen that triggered the fear?

Take action.

- Validate the individual's feelings.
- Get into the person's reality.
- Take time.
- Sit down.
- Listen.

Amanda Bacon is a brain injury survivor at age 54. She follows you around all day as you work on your tasks. You suspect that she might be afraid to be left alone. How can you support Amanda using the three-step process?

Step 1:

Step 2:

Step 3:

Unsafe Smoking

The individual might experience:

- Burns cigarettes down to fingertips
- Smoking in unauthorized areas
- Not using ashtrays or other containers
- Smoking when using oxygen
- Includes instances where there is an actual, accidental fire

Stop and remain calm.

Identify what is going on.

- Has the individual been assessed for safe smoking?

Take action.

- Behavior requires immediate attention
- Keep the individual safe
- Be familiar with resident rights
- Assess for safe smoking

Esperanza Webb, 84 has smoked most of her life. You find her smoking in bed – something that she claims she has always done and you can't stop her. How can you support Esperanza using the three-step process?

Step 1:

Step 2:

Step 3:

Up at Night While Others are Sleeping and Requires Interventions

Some individuals with TBI might be awake at night, requiring interventions. This may be part of their TBI or it may be their normal pattern of behavior. Everyone's sleep patterns are different and care should not be determined by your own patterns and expectations of sleep.

The individual might experience:

- Being awake and calling out and not getting up
- Being awake and out of bed
- Moving around when others are sleeping and disturbing the social environment

Stop and remain calm.

Identify what is going on.

- Is the behavior related to delirium?
- Is the individual sick in some way?
- Did the person work graveyard shift in the past?
- What are the patterns and norms for the individual?

Take action.

- Reduce risks of injury – darkness is a hazard overnight and increases risk of falls.
- Establish a plan for nighttime activity.
- Check on caffeine intake, particularly in the afternoon and evening.
- Ensure that the individual is getting enough fresh air and exercise.
- Make sure the individual is not sleeping during the day.
- Establish a consistent sleep schedule.

Lindsey Ferguson worked for the last 30 years of her life at a sawmill on graveyard shift. She recently survived a brain injury at the age of 61 from domestic violence. She wants to sleep all day and be awake all night. At night, she is moving around and disturbing others while she tries to find things to do. How do you support Lindsey using the three-step process?

Step 1:

Step 2:

Step 3:

Verbally Abusive

Communication, emotion and behavior could be impacted by damage to the brain. Some individuals may become verbally abusive.

The individual might experience:

- Threatening
- Screaming
- Cursing

Stop and remain calm.

Identify what is going on.

- Is there a pattern?
- What lead up to the behavior?

Take action.

- Take a time out and come back later

Craig Friedlander has a concussion. He has been having a lot of head pain and nausea. He is currently yelling and threatening another individual who is watching television in the living room. How do you support Craig and the other individual using the three-step process?

Step 1:

Step 2:

Step 3:

Wanders and is Exit Seeking

Wandering is a behavior when an individual moves about with no seemingly discernible, rational purpose. A person who wanders may be oblivious to his/her physical or safety needs. Wandering behavior is different from purposeful movement (e.g., a hungry person moving about their living area in search of food). Wandering may be by walking or wheelchair. This does not include pacing back and forth.

This behavior is focused on wandering and is exit seeking or gets outside or off the property. This is different than wandering related to boredom or a need for movement.

The individual might experience:

- Attempting to exit building.
- Wandering to find exit.

Stop and remain calm.

Identify what is going on.

- What is the individual trying to do? They may be trying to go home or to work.
- Was wandering part of the individual's history?
- Does the person need fresh air?
- What need is not being met?
- Are they looking for someone or something?

Take action.

- Use redirection or distraction if the situation is calm.
- Use validation.
- Schedule walks.
- Engage in conversation to get additional clues to get more information.

Anthony Smith wanders each evening down the halls, opening doors, looking inside. He used to be a police chief and he is very concerned with security. How can you support Anthony using the three-step process?

Step 1:

Step 2:

Step 3:

Lesson Summary

- Depending on what part or parts of a person's brain are injured, the individual may experience significant behavioral and emotional changes.
- Individuals with a TBI use behaviors to communicate a personal need, feelings and emotions.
- Your primary role is to remain and appear calm and supportive and do not take the behaviors personally.
- When you are faced with an unexpected behavior, take a moment to stop yourself and take a pause from the situation.
- Sometimes what you may see as a challenging behavior may be the only way the individual can tell you that they need or want something.
- The best way to deal with challenging behaviors is to adapt as you go to each unique individual and situation.
- In any situation, the only thing you have complete control over is yourself.

Checkpoint

Instructions: Read the scenarios below. Using the three-step strategy for approaching behaviors, select the answer that is most appropriate for each step.

Eileen Hardy, a survivor of TBI is currently having problems regulating her emotions and on occasion, she becomes combative during care. Today, as you approach, she pushes you away. How do you approach using step two: **identify**.

- A. Respectfully soothe, distract or steer her away from what triggered the behavior.
- B. Listen to what she is communicating through body language, words and emotions behind her actions.
- C. Detach yourself from the emotions of what is happening around you.
- D. All of the above.

William Larson, a survivor of TBI has been angry and frustrated lately. Today, as you enter the room, you see William shout angry words at another individual in the room. How do you approach using step three: **take action**.

- A. Respectfully soothe, distract or steer him away from what triggered the behavior.
- B. Listen to what he is communicating through body language, words and emotions behind his actions.
- C. Detach yourself from the emotions of what is happening around you.
- D. All of the above.



Module 4: Communication

The caregiver will demonstrate the ability to recognize communication styles and methods to communicate effectively with brain injury survivors, families of survivors and other professionals.

Module 4: Communication

Objective

The caregiver will demonstrate the ability to recognize communication styles and methods to communicate effectively with brain injury survivors, families of survivors and other professionals.

Overview

It is very common for communication skills to be affected by a brain injury. Difficulties with communication can be caused by many factors, including changes in behavior and thinking skills, problem solving, judgement, reasoning, awareness, memory loss and lack of self-awareness. Language ability and speech may also be affected by brain injury.



Social Communication

The most common problem for individuals with a brain injury is social communication.

Social communication is the process of interacting with another person in order to exchange information and experiences with others. Social communication requires using many cognitive abilities at the same time. A brain injury may affect some of these abilities, leading to difficulties communicating with others.

A lack of communication skills can lead to difficulty forming and maintaining relationships.

This may also create difficulty communicating effectively with caregivers.

What are some of the problems that you experience when talking to other people?

Is having a conversation harder in some situations than in others? What were those situations?

What do you do to practice and improve your communication skills?

Communication Tips for Caregivers

Communicate clearly

A brain injury survivor may be less able to understand and sympathize with the feelings of others than before they had a brain injury. The individual may be less skilled at communicating emotions to others. They also may not understand the unspoken parts of conversation such as body language and facial expressions. It may be necessary to describe your feelings to them very directly and clearly.

Provide support and opportunities to practice

Before participating in social activities, give the person information ahead of time and possibly rehearse possible social situations that might come up. Be aware that a brain injury survivor is not always able to adapt to the environment and behave differently in public than at home, for example. It may help if you describe the appropriate behavior.

Be kind when giving constructive feedback

When giving feedback, it is always important to do so in a polite and respectful manner and to point out what they did well. Give examples of how the situation could have been handled better.

Have realistic expectations

Do not expect behavior to change because the activity is important to you. Be patient and remember that the person with a brain injury is doing the best they can. Communication problems often get better with time.

Read the conversation below and answer the questions that follow.

Stan: I had an exciting day today. I had a job interview at a clothing store and I think it went really well.

Bob: I went in there once to buy a pair of pants when they had a sale going on and I couldn't find a pair in my size. The only pants that they had that I liked were extra-large! I may have gained some weight recently, but I am not extra-large. My uncle, on the other hand was a really big guy – he probably wore extra-large.

Stan: So anyways, I think I might get the job. The boss seemed to really like me.

Bob: I had a job once that I was really good at and I thought the boss really liked me but then I got fired.

Stan: I've got to go, see you around.

- Why did Stan leave so abruptly?
- What went wrong in his conversation?
- What could Bob have said differently?
- What if Stan is the caregiver?
- What if Bob is the caregiver?

Communicating with TBI Survivors



After a brain injury, there may be changes in one or many areas of the brain. The severity and combination of problems vary widely among individuals. It is important to involve the individual when communicating information and making decisions. Sometimes limiting the number of choices can make a big difference. The individual may have speech impairments or behaviors that make communication more challenging.

The survivor may have difficulty:

- Initiating conversation
- Following conversation
- Taking turns in conversation
- Difficulty with intelligibility (annunciating)
- Nonverbal communication

Initiating conversation

The survivor who has trouble initiating conversations has difficulty:

- Responding to conversation, questions or comments
- Slow to start conversations, ask questions or make comments
- Leaves long pauses
- Has difficulty with explanations

Strategies to support the survivor:

- Encourage participation from the individual in conversation by asking open-ended questions.
- Give the individual time to process the information and organize thoughts. Extra time may be required to receive a response.
- Give the individual your full attention until the thought is completed.
- Rephrase what the individual said.
- Encourage the individual to keep a list of conversation topics as inspiration.
- Encourage the individual to let you and others know that they are having difficulty and have some strategies to share with others (if known) that can be helpful to assist.

Following conversation

The survivor who has trouble following conversation has difficulty:

- Paying attention to what is said
- Misinterprets what is said

Strategies to support the survivor:

- Get the individual's attention before speaking.
- Be clear and concise.
- Reduce distractions.
- Emphasize important information.
- Offer to repeat what was said.
- Ask the person to look at you when speaking.
- Invite the person to ask questions or request clarification.
- Ask the person to relay the information back to you in their own words to ensure they have understood what you are trying to tell them.
- Encourage them to look at the person who is speaking to them.
- Speak slower.

Taking turns in conversation

The survivor who has trouble taking turns in conversations has difficulty:

- Talking non-stop, does not give the listener a turn to speak.
- Does not appear to adjust communication.
- Has difficult time selecting topics for conversation.
- Has a difficult time keeping up with transitions, or when topics change.
- Introduces a new topic abruptly.
- Does not always stay on topic.

Strategies to support the survivor:

- Politely interrupt and ask for a chance to speak.
- Ask the person to please make it brief or announce that you would like to speak.
- Ask about the person's interests and opinions.
- Clarify new topics as they arise.
- Ask how the person's comment relates to the topic, for example, "Do you mean...".
- Tell the person you are confused or getting lost in the conversation.
- Encourage the individual to set a timer while talking.
- Encourage to ask clarifying questions if they do not understand when the conversation topic has changed.

Difficulty with enunciating

The survivor who has difficulty with enunciating may:

- Slur speech
- Speak too loudly or softly, making the message hard to understand
- Speaks too rapidly

Strategies to support the survivor:

- Tell the individual you did not understand and ask to hear it again.
- Establish and use consistent gestures or cues.
- Encourage the individual to ask for cues when speaking too soft, loud or fast.

Nonverbal communication

The survivor who has trouble with non-verbal communication has difficulty:

- Understanding common non-verbal cues
- Standing too close or too far from conversational partner(s)
- Using body language to match what is said
- Facial expressions not matching what is said
- Distracted, repetitive or excessive body movements
- Eye contact
- Staring at others during conversation

Strategies to support the survivor:

- Ask the person to maintain a comfortable distance.
- Politely ask the person to modify their physical contacts because you feel uncomfortable. Offer an explanation if necessary.
- Tell the person you are confused by the difference in body language and spoken message.
- Ask what the person is feeling.
- Politely ask the individual to stop distracting movements.
- Encourage the individual to ask for cues when they are standing too close or too far.
- Encourage the individual to be mindful if a lack of eye contact is occurring.
- Encourage the individual to be up front about their bubble/personal space.

George Griffith, a 58-year-old man with a brain injury, has the following challenges with communication:

- Leaves long pauses in conversation
- Has difficulty paying attention to the conversation
- Often goes off topic
- Speaks too loudly
- Stands too close

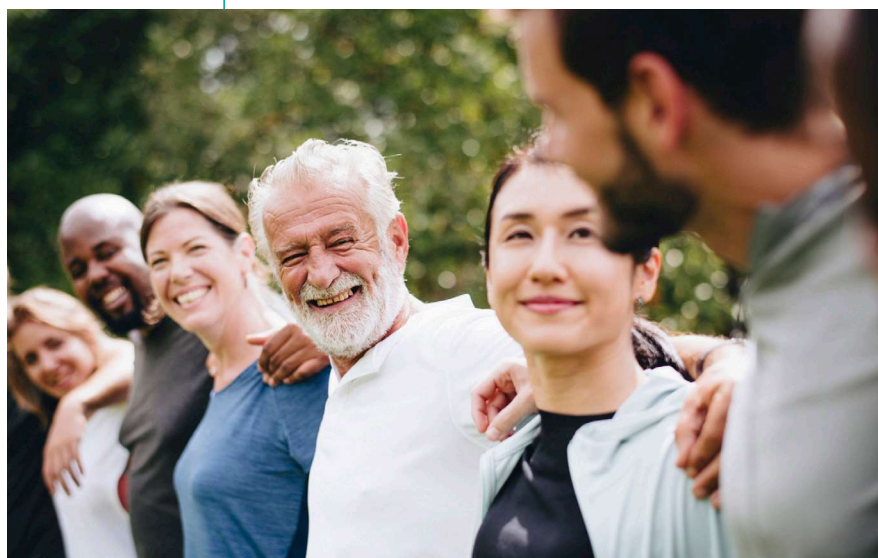
How can you support George?

Cultural Diversity and Communication

Delivering quality care to culturally diverse populations is an increasing challenge for caregivers.

Some strategies to help support the individual:

- Understand your own values and assumptions and consider the differences between the two and understand that good communication comes from speaking to the others culture.
- Be aware of the individuals' cultural beliefs.
- Be an effective communicator – this may involve interpreters and translators.



There are good resources and training available on cultural competency. Talk to your manager for additional training or check out one of these resources online:

- EthnoMed | ethnomed.org
- Cross Cultural Health Care Program | xculture.org

Communicating With the Family or Family Members

Information about brain injury is the number one need reported by families, yet educating families about brain injury is complicated. The brain is so complex that it is difficult to predict recovery. Each brain injury is unique.



Involve the family

- Treat families as team members with valuable knowledge about the survivor prior to the brain injury.
- Involve the family in developing and implementing a care plan.
- Help families feel confident by acknowledging the accuracy of their observations and their ability to care for the individual with a brain injury.
- Admit it when you do not know the answer to a question and reassure families that their questions are valid.
- Encourage families to record information using methods that are easy for them to remember such as note taking, journaling, voice or video recording.
- Maintain regular communication with the family as the individual progresses.
- Ask the family to identify one person to be the primary link for communication and know how to contact the person.
- Involve families in planning.

Supporting families

- Ask families about their feelings and give them time to talk about them. Unexpressed feelings can block communication and learning.
- Recognize the normal stages of grief for families and that the family is grieving and what that may mean to their involvement. Stages include denial, anger, bargaining, depression and resolution. You may see the full range or the early stages.
- Expect anger or conflict from families. It is a normal part of grieving. Do not take it personally or retaliate if you are the target for a family's emotions.
- Respect spirituality of families.

- Give families tasks to help them cope with their anxiety and acknowledge the contributions they make. Examples are rubbing body lotion, reading stories and teaching simple exercises.
- Manage the family's expectations for progress.

When there is no family

Relationships may be difficult to maintain after a brain injury or there may be no family to begin with. Encouraging support groups and building support networks for the individuals with brain injury is important for health and well-being.

Support groups:

- Help people feel less isolated
- Provide practical knowledge, resources and networking
- Help answer questions

Discuss other ways you can communicate with and support the families of survivors of brain injury.

Communicating with Professionals

You may or may not need to communicate with professionals in your role caring for an individual with a brain injury. Some of these professionals are listed in Module 2 and quality of life therapies on page 23.

When communicating with these professionals, remember:

- You are advocating for the individual with medical professionals.
- Know your policies around how and when to step in.
- Be aware of who to contact and who to call.
- Learn what the limitations are and what questions to ask.



Document and Report

Professional caregivers may have important information to share with other team members. Others on your team need to understand and learn from what you observed, what actions you took and what did and did not work and why.



There will be policies and procedures for documenting and reporting that you must follow. Objectively writing down what happened and what actions you took gives everyone a record. This record will help make sure you do not forget even small details, that when reviewed again, might reveal important information.

Lesson Summary

- It is very common for communication skills to be affected by a brain injury.
- A lack of communication skills can lead to difficulty forming and maintaining relationships.
- A brain injury survivor may be less able to understand and sympathize with the feelings of others than before they had a brain injury.
- Treat families as team members with valuable knowledge about the survivor prior to the injury.
- Know and follow the documentation policy in your setting.

Checkpoint

Instructions: Read the scenario carefully. For each question that follows, choose the best answer from the options listed. When all answers provided are correct, choosing “all of the above” is the best answer.

You recently started providing care for Pearl Caldwell. Pearl will be 54 years old this January. Before her injury, she worked as a landscape designer and loved working with plants and people. Lately she has been spending more time alone. Today, you invite her outside to walk in the garden.

How might you communicate with Pearl if she has trouble initiating conversation?

- Rephrase what Pearl says.
- Encourage participation from Pearl by asking open-ended questions.
- Give Pearl time to process the information and organize her thoughts.
- All of the above.

How might you communicate with Pearl if she has difficulty following conversation because she has trouble paying attention to what is said?

- Get Pearl’s attention before speaking.
- Reduce distractions for Pearl.
- Emphasize important information given to Pearl.
- All of the above.



Module 5: Self-Care

The caregiver will create a self-care plan broken down into smaller action steps to reach a goal for better self-care.

Module 5: Self-Care

Objective

The caregiver will create a self-care plan broken down into smaller action steps to reach a goal for better self-care.

Overview

Caregiving is a rewarding yet physically and emotionally challenging profession. It is critical that you take care of yourself so you are at your best for others. Most of us know that self-care is important and yet we still put ourselves last in a long line of people we care for. Making self-care a priority will help you maintain a better sense of wellness, help prevent secondary trauma and burnout.



How Caregiving Affects Health and Well Being

Secondary trauma (also known as compassion fatigue) describes trauma-related stress reactions and symptoms resulting from exposure to another individual's traumatic experiences, rather than the exposure directly to a traumatic event. Secondary trauma can occur among caregivers who provide services to those who have experienced trauma.

Symptoms of secondary trauma:

- Intrusive thoughts
- Chronic fatigue
- Sadness
- Anger
- Poor concentration
- Second guessing
- Detachment
- Emotional exhaustion
- Fearfulness

- Shame
- Physical illness
- Absenteeism

Prevent secondary trauma by practicing personal wellness techniques and establish a diverse social support network.

In a seated position with your back straight, place your hands in your lap. Allow your attention to focus on the tightness in your neck and shoulders. As you slowly breathe in, tighten and rotate your neck and shoulders pulling them up as though you could touch your ears. Visualize all of your breath and energy going straight to where you feel your stress and tension. Hold this position for just a moment as you visualize the tension and stress breaking into tiny pieces. With a gush of relief, allow all of your breath and tension to rush out with your breath as you drop your shoulders. Slowly and deeply take in a deep refreshing breath visualizing the oxygen filling, soothing and re-energizing every nerve and cell in your body. Slowly exhale and repeat the exercise as needed.

Take Responsibility for Your Own Care

Over time, you may feel overwhelmed, exhausted, frustrated, resentful and guilty. Do not ignore the signs of burnout in yourself or other caregivers.

Take this stress test. If the statement is true, circle T. If the statement is false, circle F.

- T F** I have a lot to do.
- T F** I have more to do than I can handle.
- T F** I'm not being productive.
- T F** I'm trying really hard but getting nothing done.
- T F** I'm feeling unhealthy.
- T F** I can't afford to take breaks or time off.
- T F** I'm pushing myself too hard.
- T F** I don't sleep very well.
- T F** Too many people are telling me what to do.
- T F** I am not treating people the way I want to be treated.
- T F** I feel totally exhausted.
- T F** Nobody is happy with what I do.
- T F** I cannot stand living like this.

If you answered all F's then you are stress free or maybe fooling yourself. The more T's you circle, the greater your level of stress and the more you need to think about taking steps to change.

Here are some ideas to help you better deal with stress.

- Put your physical needs first
- Eat nutritious meals
- Get enough sleep
- Schedule regular medical checkups
- Connect with friends
- Ask for help
- Take time to break and rest
- Seek support for your feelings
- Talk about your emotions
- Plan ahead and be proactive instead of reactive
- Find time to relax
- Set goals
- Get organized
- Just say no
- Stay positive
- Evaluate the situation
- Understand mixed feelings is OK
- Understand that you cannot create or cure illness

What are other healthy ways to deal with stress?
What about unhealthy ways?



Goals and Self-care Planning

A self-care plan can help you enhance your health and wellbeing, manage your stress and maintain a high level of quality care for individuals with a brain injury.

Some aspects of self-care might include:

- Workplace or professional
- Physical
- Psychological
- Emotional
- Spiritual
- Relationships

On page 63, complete the self-care plan with activities that are meaningful for you personally and your own goals.

Share your self-care plan with a trusted mentor, a close friend or family member for accountability.

Keep this plan in a place where you can see it daily. Practice the activities regularly. Reassess how you are doing at the end of one month, three months, and longer.

Examples of self-care

Workplace or professional self-care (Work)

This involves activities that help you to work consistently at the professional level expected of you. For example:

- Engage in regular supervision or mentoring with a more experienced colleague
- Set up a peer-support group
- Be strict with boundaries
- Read professional journals
- Attend professional development programs

Physical self-care (Body)

Activities that help you to stay fit and healthy, and with enough energy to get through your work and personal commitments.

- Develop a regular sleep routine.
- Aim for a healthy diet.
- Take lunch breaks.
- Go for a walk at lunchtime.
- Take your dog for a walk after work.
- Use your sick leave.
- Get some exercise before/after work regularly.

Psychological self-care (Mind)

Activities that help you to feel clear-headed and able to intellectually engage with the professional challenges that are found in your work and personal life.

- Keep a reflective journal.
- Engage with a non-work hobby.
- Turn off your email and work phone outside of work hours.
- Make time for relaxation.
- Make time to engage with positive friends and family.

Emotional self-care (Emotions)

Allowing yourself to safely experience your full range of emotions.

- Develop friendships that are supportive.
- Attend caregiver support groups.
- Write three good things that you did each day.
- Play a sport and have a coffee with a friend after training.

- Go to the movies or do something else you enjoy.
- Talk to a friend about how you are coping with work and life demands.

Spiritual self-care

This involves having a sense of perspective beyond the day-to-day of life.

- Engage in reflective practices like meditation.
- Spend time in nature.
- Go to church/mosque/temple.
- Do yoga.
- Reflect with a close friend for support.
- Download a mindfulness or meditation app on your smart phone.

Relationship self-care

This is about maintaining healthy, supportive relationships and ensuring you have diversity in your relationships so that you are not only connected to work people.

- Prioritize close relationships in your life, e.g. with partners, family and children.
- Attend the special events of your family and friends.
- Arrive to work and leave on time every day.

Lesson Summary

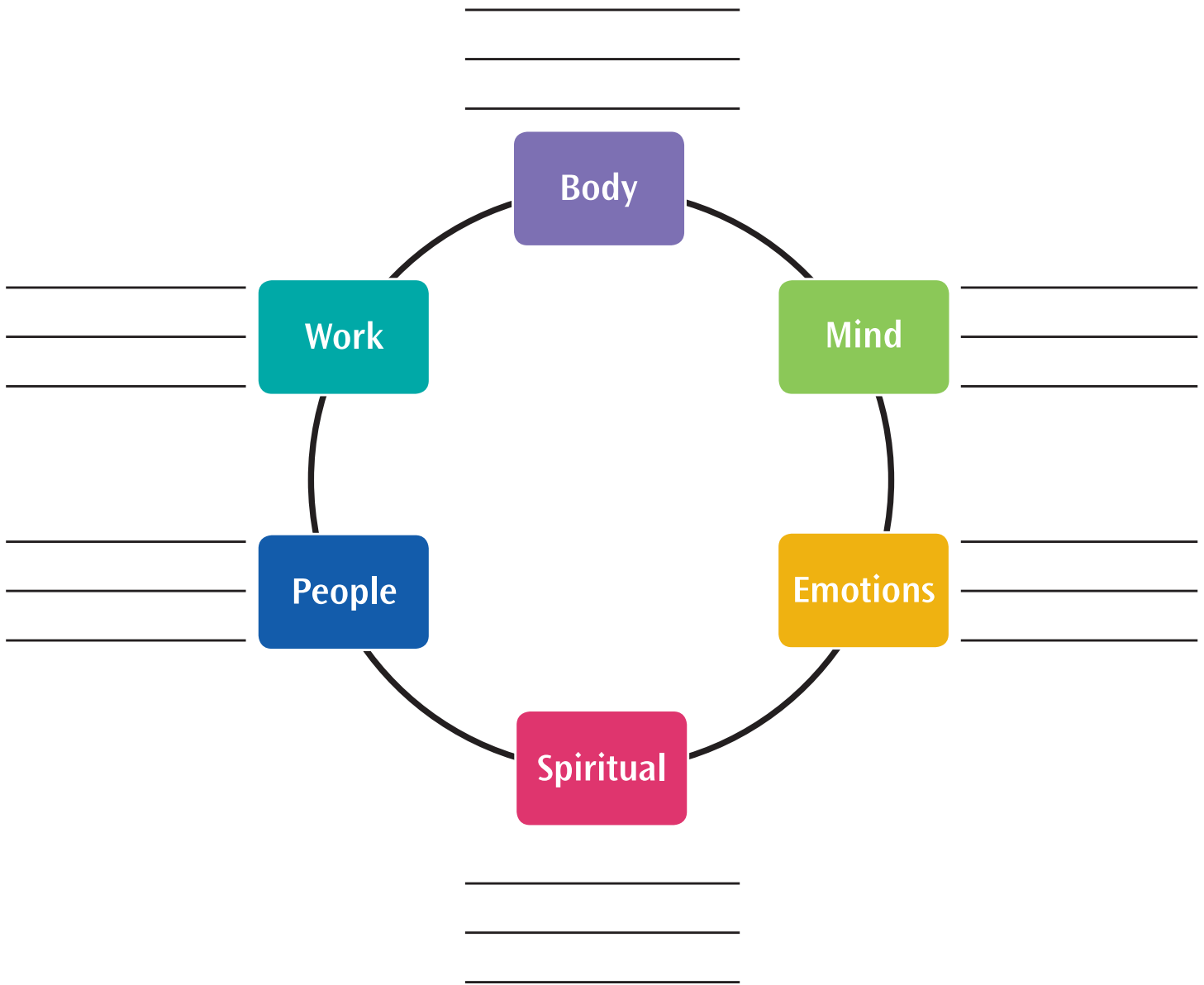
- Caregiving can be a rewarding yet physically and emotionally challenging.
- Secondary trauma can occur among caregivers who provide care to those who have experienced trauma.
- Over time, you may feel overwhelmed, exhausted, frustrated, resentful and guilty. Do not ignore the signs of burnout in yourself or other caregivers.
- Create a self-care plan to help you enhance your health and wellbeing, manage your stress and maintain a high level of quality care for individuals with a brain injury.
- Care for all areas of your life: body, mind, emotions, spiritual, relationships and work.

Checkpoint

Instructions: Read the statements below and indicate if they are true or false.

	True	False
Secondary trauma can occur because of exposure to another individual’s traumatic experiences.		
Symptoms of secondary trauma may include anger, shame and physical illness.		
It is good to put other people’s needs before your own.		
Setting goals can help you better deal with stress.		

Self-care Plan



Overall Balance:

What might get in my way?

What negative strategies do I need to avoid?

If I implement this plan, how might I feel?

Resources

6 steps for preventing falls among your older loved ones | National Council on Aging (NCOA)

Retrieved from <https://www.ncoa.org/healthy-aging/falls-prevention/preventing-falls-tips-for-older-adults-and-caregivers/6-steps-to-protect-your-older-loved-one-from-a-fall/>

Anoxic Brain Injury – BrainAndSpinalCord.org | Brain & Head Injury Trauma

Retrieved from <https://www.brainandspinalcord.org/anoxic-brain-injury/>

Apraxia | Wikipedia

Retrieved from <https://en.wikipedia.org/wiki/Apraxia>

Behavioral and Emotional Effects After TBI | Brainline

Retrieved from <https://www.brainline.org/article/behavioral-and-emotional-effects-after-tbi>

Bladder and Bowel Changes | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Bladder-and-Bowel-Changes>

Brain Injury: What you need to know | Brain Injury Alliance of Washington (BIAWA)

Retrieved from <https://www.biawa.org/asset/5ba1480b3a6af>

Brain Injury: What you need to know. A guide for survivors of brain injury, their loved ones, caregivers and the professionals who serve them. | Brain Injury Alliance Washington 2018

Challenging & Complex Behaviours – Anger | Synapse

Retrieved from <https://synapse.org.au/information-services/anger-angry-outbursts-after-a-brain-injury.aspx>

Cognitive Problems After Traumatic Brain Injury | Brainline

Retrieved from <https://www.brainline.org/article/cognitive-problems-after-traumatic-brain-injury>

Cognitive Problems after Traumatic Brain Injury | Model Systems Knowledge Translation Center (MSKTC)

Retrieved from <https://msktc.org/tbi/factsheets/Cognitive-Problems-After-Traumatic-Brain-Injury>

Cueing | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-Two/Memory-Compensation/Cueing>

Current Psychiatry. Traumatic brain injury: choosing drugs to assist recovery. Some agents can worsen neurobehavioral symptoms. | John P. Daniels, MD.

Retrieved from https://mdedge-files-live.s3.us-east-2.amazonaws.com/files/s3fs-public/Document/September-2017/0505CP_Article4.pdf

Emotional Problems after Traumatic Brain Injury | MSKTC

Retrieved from <https://msktc.org/tbi/factsheets/emotional-problems-after-traumatic-brain-injury>

Energy Management for Caregivers | Karl LaRowe

Retrieved from <http://socialwork.buffalo.edu/content/dam/socialwork/home/self-care-kit/exercises/energy-management-for-care-providers.pdf>

Facts about Concussion and Brain Injury | Brain Line

Retrieved from <https://www.brainline.org/article/facts-about-concussion-and-brain-injury>

Facts about Developmental Disabilities | CDC

Retrieved from <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>

Fatigue | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Fatigue>

Fatigue and Traumatic Brain Injury | Model Systems Knowledge Translation Center (MSKTC)

Retrieved from <https://msktc.org/tbi/factsheets/fatigue-and-traumatic-brain-injury>

Functional Independence Measure | METeOR

Retrieved from <https://meteor.aihw.gov.au/content/index.phtml/itemId/495857>

Headaches | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Headaches>

Heterotrophic Ossification | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Heterotrophic-Ossification>

Laughter Therapy for Brain Injury | Laughter Yoga University

Retrieved from <https://laughteryoga.org/laughter-therapy-for-brain-injury/>

Laughter therapy has its perks for brain injury patients | Global News

Retrieved from <https://globalnews.ca/video/rd/208411715937/?jwsourc=cl>

Living – Activities and skills | Working with people with traumatic brain injury

Retrieved from http://www.tbistafftraining.info/selfstudy/Module_3/3.1.htm

Lost & Found: Dealing with Sensory Overload after Brain Injury | Brain Line

Retrieved from <https://www.brainline.org/article/lost-found-dealing-sensory-overload-after-brain-injury>

Love Your Brain Foundation.

Retrieved from <http://www.loveyourbrain.com/>

Managing Stress Effectively after TBI | Brainline

Retrieved from <https://www.brainline.org/article/managing-stress-effectively-after-tbi-part-i>

Medications | Brain Injury Association of America (BIAUSA)

<https://www.biausa.org/brain-injury/about-brain-injury/treatment/medications>

Mental health and brain injury dual diagnosis | Synapse

Retrieved from [https://synapse.org.au/information-services/mental-health-brain-injury-mental-illness-\(dual-diagnosis\).aspx](https://synapse.org.au/information-services/mental-health-brain-injury-mental-illness-(dual-diagnosis).aspx)

Muscle Weakness / Immobility | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Muscle-Weakness-Immobility>

Music-based cognitive remediation therapy for patients with traumatic brain Injury. | US National Library of Medicine National Institutes of Health

Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3970008/>

My Parents' Support Shaped My Recovery | National Alliance on Mental Illness (NAMI)

Retrieved from <https://www.nami.org/learn-more/mental-health-conditions>

Physical Effects / Dizziness and Balance | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Dizziness-and-Balance>

Polypharmacy | Wikipedia

Retrieved from <https://en.wikipedia.org/wiki/Polypharmacy>

Rehabilitation for Persons with Traumatic Brain Injury | World Health Organization United States Department of Defense

Retrieved from https://apps.who.int/iris/bitstream/handle/10665/69231/WHO_DAR_01.9_eng.pdf;jsessionid=E8284300B299AB184F93734EB9E33BE1?sequence=1

Reintroduction to body and community: Dance/Movement therapy with survivors of traumatic brain injury. | American Dance Therapy Association

Retrieved from <https://adta.org/2015/04/08/reintroduction-to-body-and-community-dancemovement-therapy-with-survivors-of-traumatic-brain-injuries/>

Repetitive Behaviors | Traumatic Brain Injury CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-Two/Behavioral-and-Emotional-Effects/Repetitive-Behaviors>

Risky Behaviors and Brain Injury | Brain Line

Retrieved from <https://www.brainline.org/author/michael-paul-mason/qa/risky-behaviors-and-brain-injury>

Second TBI – The risk of subsequent brain injury. | Subtle Brain Injury

Retrieved from <http://subtlebraininjury.com/secondtbi/>

Seizures | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Seizures>

Self-injury (Cutting, Self-Harm or Self-Mutilation) | Mental Health America

Retrieved from <https://www.mentalhealthamerica.net/self-injury>

Sensory Changes | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Sensory-Changes>

Sexuality after Traumatic Brain Injury | UWMSKTC

Retrieved from http://uwmsktc.washington.edu/sites/uwmsktc/files/files/TBI_sexuality.pdf

Sleep Disturbances / Insomnia | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Sleep-Disturbances-Insomnia>

Speech Therapy. | Brain Injury Education

Retrieved from <http://braininjuryeducation.org/Treatment/Speech-Therapy/>

Substance Abuse and Traumatic Brain Injury | Brain Line

Retrieved from <https://www.brainline.org/article/substance-abuse-and-traumatic-brain-injury>

Swallowing / Appetite & Weight | CEMM Library.

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Swallowing-Appetite-Weight>

TBI 101: Behavioral & Emotional Symptoms | Brain Line

Retrieved from <https://www.brainline.org/article/tbi-101-behavioral-emotional-symptoms>

TBI and Occupational Therapy | Brain Injury Education

Retrieved from <http://braininjuryeducation.org/Occupational-Therapy/tbi-and-occupational-therapy.html>

TBI and PTSD: Navigating the Perfect Storm | Brain Line

Retrieved from <https://www.brainline.org/article/tbi-and-ptsd-navigating-perfect-storm>

TBI and suicide | Mental Illness Research, Education and Clinical Centers (MIRECC)

Retrieved from https://www.sprc.org/sites/default/files/migrate/library/TBI_Suicide.pdf

The Brain Injury Guide and Resources Behavioral / Emotional Issues | Brain Injury Education Org

Retrieved from <http://www.braininjuryeducation.org/TBI-Basics/Behaviorial-and-Emotional-Impacts-of-TBI/>

The recovery process for traumatic brain injury | Model Systems Knowledge Translation Center (MSKTC)

Retrieved from <https://msktc.org/tbi/factsheets/Understanding-TBI/The-Recovery-Process-For-Traumatic-Brain-Injury>

Traumatic Brain Injury & Concussion | CDC

Retrieved from <https://www.cdc.gov/traumaticbraininjury/index.html>

Traumatic brain injury | Mayo Clinic

Retrieved from <https://www.mayoclinic.org/diseases-conditions/traumatic-brain-injury/symptoms-causes/syc-20378557>

Traumatic Brain Injury Fact sheets | Washington State Department of Social and Health Services, ALTA

Traumatic Brain Injury. Strategies for Surviving and Thriving. Spring 2009 | Washington Department of Social and Health Services

Understanding TBI | Model Systems Knowledge Translation Center (MSKTC)

Retrieved from https://msktc.org/lib/docs/Factsheets/TBI_Understanding_TBI_part_3.pdf

Visual Problems | CEMM Library

Retrieved from <https://tbi.cemmlibrary.org/The-Caregiver%E2%80%99s-Journey/Chapter-One/Physical-Effects/Visual-Problems>

What Exactly Does the “Mild” in Mild Traumatic Brain Injury Mean? | Brain Line

Retrieved from <https://www.brainline.org/article/what-exactly-does-mild-mild-traumatic-brain-injury-mean>

Yoga and meditation for brain injury. | TBI Therapy

Retrieved from <https://tbitherapy.com/yoga-meditation-brain-injury/>

Videos

Five Important Lessons on the Five Year Anniversary of my Brain Injury | Adventures in Brain Injury
www.Adventuresinbraininjury.com

Burden of a Concussion | Inside Science
www.Insidescience.org

Jason Poole
Washington State DSHS

What is Trauma-Informed Care? | Center for Health Care Strategies
www.Traumainformedcare.chcs.org

TBI Success Story
Washington State DSHS

TBI Awareness: The Benefits of Art Therapy | Military Health
www.Health.mil

6 Quick Laughter Yoga Exercises that Access the Now
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