Brain Injury Education

What you need to know about your loved ones injury and resources to help understand how to care for them even after discharge.

Information to help increase your knowledge of brain injury.
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Teach-back questions

1. We may refer to your loved ones “Ranchos” level often during their stay. Tell me why this scale is important to the healthcare team? Show me where you will look for suggestions about each level.

2. What kind of things can you do to keep your loved one safe when you go home? What is 24 hour supervision?

3. Tell me 2 things you can do while your loved one is here to help their fatigue and tiredness? What 2 things can you do when you get home?

4. List 3 things that are important to remember about driving after a brain injury.

5. (IF applicable) What are two things you can do to keep your loved one safe during a seizure? Tell me what you can do to help prevent seizures.
Learning About Brain Injury

The rehab team at UnityPoint St. Luke’s would like to give you the tools to help you fully understand what it means when you have been told that you or a loved one has a “brain injury”

A video presentation that may be helpful for you and is available on the nursing unit titled: “Understanding BRAIN INJURY”. This same film can be viewed at home (or in the patient education room) on any computer at: www.BrainInjury101.org

Please note that you will need to select either chapter 3 or 4 when viewing this film.
- Chapter 3 addresses a brain injury from a traumatic event (when the head was hit from an outside force and the brain was damaged).
- Chapter 4 addresses brain injury that was not caused by a trauma but by a stroke, cancer, illness or infection.

Written information is also available. The Brain Injury Alliance of Iowa is a great resource for information. They have developed a bag of written information that will be helpful through all stages of the recovery process. You should have received this bag before you arrived on the Rehabilitation Unit. If you have not, or would like additional bags, please let us know.

Other web sites that may be helpful are:
http://www.msktc.org/ -This site is researched based and is very reliable
http://www.traumaticbraininjuryatoz.org/ -This site has more information that will help you understand the area of the brain that was damaged. It tells why the problems are present as they relate to the area of the brain that was injured. Please ask your nurse or Care Coordinator for details about the exact areas of injury if you do not know what they are.
http://www.brainline.org/multimedia/interactive_brain/the_human_brain.html -This site is interactive and if you place the cursor on the brain, it tells you what that area of the brain does.

Please ask questions since we are all here to help you through this journey!
Brain Injury and Causes

**What is a brain injury?**

A brain injury (head injury) occurs when part or parts of the brain are damaged. The brain is no longer working in a “normal” way. The amount of damage will depend on which area and the amount of the brain that is damaged. The part of the brain damaged may be limited to one area of the brain or can be all over the brain.

**What causes brain injury?**

A brain injury can result from the following:

- A blow to the head during a car or bike accident.
- A fall.
- Gunshot wound.
- Infection.
- Tumor (cancer).
- When the brain does not get enough oxygen.

**Damage to the brain can be from different causes:**

- Injury to the head from the blow.
- The swelling from the injury (swelling or bleeding in the brain).
- Swelling from surgery.
- Damage from abnormal cells such as cancer.
- Lack of oxygen to the brain – when the blood does not get to the brain.
Injury to the head can be a result of different reasons:

Directly from when the brain hits the skull during the accident.

When the brain is hit on one spot it bounces back and hits against the opposite side of the skull, causing more damage. This is called a **countercoup** injury.

Sometimes when the injury happens while in motion (when in a moving car or bike) the brain can actually twist inside of the skull, causing **tearing or shearing** of the brain tissue. The very bottom of the brain (the brain stem) can be pulled. The brain stem helps us stay awake and talk or follow commands. When the brain is shaken small areas all over the brain can be injured this is called a **diffuse** brain injury.

When blood does not flow to the brain to supply the brain tissue with needed oxygen and nutrients, this is called **anoxic** brain injury.
Stages of Recovery

Rancho Los Amigos Scale:

The Rancho level of cognitive function scale is an eight-level scale that was developed several years ago and is named after a California hospital known as the Rancho Los Amigos National Rehabilitation Center. It is a well-known and well researched tool used by medical personnel for understanding patterns of recovery and impairment for people with traumatic brain injury in the first year after the injury. The scale describes behavior and thinking problems that commonly occur after traumatic brain injury. We use the scale to help design an appropriate treatment program in rehab.

What are the stages of recovery?

After a brain injury, your loved one will typically go through different stages of mental (thinking) and emotional recovery. Each person will go through these stages in their own way. The different stages of recovery can last a few hours or a few weeks. They may also have signs of being in two stages at once. They can go back and forth between stages and some will even skip a stage.

These stages of recovery are helpful to both staff and family. They help us understand what behaviors to expect, how to interact positively and how to help the person as they recover.
There are eight stages of recovery:

The first three stages of recovery occur when your loved one is not responding very well.

**Stage 1: No response**

- Your loved one appears to be in a deep sleep and does not respond to what is going on around them. Eyes can be open or closed.

**Stage 2: Generalized response**

- Your loved one begins to respond in a very general way when the rehab team or family tries to wake them up.
- Responses are seen with more movements, sweating, higher pules and breathing rates.
- Responses may be small changes and may take a long time.

**Stage 3: Localized response**

- Your loved one may experience the following
  - May begin to be more aware.
  - They will respond specifically to efforts to help waken them. The response may be an attempt to talk or pull away.
  - May be able to follow directions if very simple, such as “close your eyes” or “squeeze my hand”.
  - May not respond every time you try to get a respond.
  - May or may not know who family or good friends are.
- Because of possible memory problems they can be scared or confused.
The following stages describe what can be seen as the person is more awake and starts to respond.

**Stage 4: Confused / Agitated**

- Your loved one may experience the following:
  - Can be excitable (emotional, edgy), yell or shout out to family or caregivers, or can hit at caregivers. This behavior is usually because of confusion, fear and not knowing where he or she is or what has happened.
  - Have a very short attention span. They can listen and hear only seconds at a time. They cannot remember new information. They do not know, nor remember they are in the hospital. They usually do not remember new names.
  - They may remember family members but not every time.
  - They can get mixed up in conversation and may call object or people by the wrong names. He or she may get mixed up with how to use things such as a toothbrush – brushing the hair rather than the teeth.

- This is a stage where the brain injured person is very confused. They may think they can do things that they cannot. They might think they can walk to the bathroom when they are too weak or should not walk because of medical reasons, for example.

- They may need measures to keep them safe such as a net bed, soft restraints, alarms and close supervision.
Things to work toward during stage 4:

- Gently remind your loved one where they are and that they are safe.
- Help your loved one to be calm – keep noise down (turn off the TV), limit visitors to 2 or 3 at a time. Watch to see what increases the confused or agitated behavior and avoid it. Let other caregivers know if you see any triggers.
- Help your loved one pay attention, listen and hear direction. It is wise to speak slowly and in short sentences. Give them one direction or item of information at a time. When asking questions make them short and spaced out. Wait patiently for a response; they will often need extra time to gather their thoughts.
- Bring in family pictures and personal items from home to help them feel comfortable.
- Keep them safe by use of alarms and staying with them. At this stage the staff may recommend a different bed (one with a net around it) to keep them safe.
- Provide your loved one with tasks or exercises that help them move and think. They many need frequent breaks and changes in activities as their attention span is short.

Stage 5: Confused / Inappropriate / Not agitated

- Your loved one may experience any of the following:
  - May become easily frustrated, become angry or will “give up” when asked to do something they cannot do, but were able to do easily before the accident.
  - Sometimes will do things for the family, but not for the therapy staff.
o When working on a task your loved one may only attend to the task for 2-3 minutes or less. They will become easily distracted by people around them or even by their own thoughts.

o usually **does not** know the day, month, and year or where they are.

o May remember visits from friends or family and past events, at times, but not the next hour or day. They have memory lapses.

o May have a hard time remembering and learning new information.

o May “make up” events or details to cover up their memory problems (confabulation).

o Do better with tasks and activities they have learned before the accident.

o May not be aware that they have had an injury. For example, if they have a broken bone they will forget to be careful. When they talk to their friends and family they may be confused or incorrect about events.

o May appear to have no emotions in facial expressions. When they talk they may appear almost “Robot-like”.

**Things to work toward during stage 5:**

- **Lower the confusion** – rehab staff may need to do therapy away from the big gym, limit visitors, avoid TV, and lower the noise volume. They will need time for rest breaks.

- **Review the important events in their life to help increase their memory.** When you arrive and leave, tell them the day, time and the name of the hospital.
• Redirect them to help with staying on task, this will increase attention.
• Encourage them to manage their own cares such as dressing, brushing teeth, eating, etc.
• Help them follow directions – use tools such as leaving notes or posting signs.
• Work on increasing strength and coordination.
• Gently challenge them to work on harder thinking activities, but don’t put pressure on them to do this.
• Family and staff may need to have several activities available as they may become bored and distracted easily.
• Continue to limit visitors

Stage 6: Confused / Appropriate:

• Your loved one may experience any of the following:
  o Get frustrated but is able to control their feelings and express themselves correctly. Will no longer have angry outburst when things are hard or confusing.
  o Can concentrate up to 30 minutes at a time on tasks during therapy, with supervision.
  o Becomes more aware of the time / date and where they are, but may still get mixed up at times.
  o Does best with routine. Can get confused if the routine is changed so leave messages or notes if the visiting schedule changes.
  o Can sometimes remember what they did during the day if it is a routine (going to therapy), and can remember major
events in their life (where they live, their job, etc), but do not remember details.
- Can start to learn new things with close supervision for safety but needs help to finish the task.
- Can follow simple one step directions almost all the time and can do most self-care tasks alone.
- Answers to questions may continue to be wrong but they will be more logical.
- May be able to understand that there are some problems with the way they are thinking but cannot see how the problems will affect their future. They can say they had a brain injury but still thinks they will be able to go back to work in the very near future.
- Will have a hard time knowing how to plan what they will need to do to adjust to the effects of the brain injury.
  - Can focus on learning new skills and are remembering for longer periods of time. They can use skills they have learned before the injury to help develop new ones.

**Things to work toward during stage 6:**

- Your loved one can work on harder tasks with less help. Encourage them to participate in all therapy.
- They may still think they are “better” than they actually are (poor insight).
- You may need to repeat information. Discuss what has happened during the day to aid memory.
- Developing tools to remember daily events:
  - Introducing them to using a journal to write down events.
Day planners or electronic memory aids may be introduced.
Gently remind them what has happened, what they can do and what they need help with.

**Stage 7: Automatic / Appropriate**

- Your loved one may experience any of the following:
  - Consistently remember more details of the day and what has happened from day to day. They may still have confusion about the order of events. For example, they may mix up what happened Monday with what happened Tuesday.
  - Usually remembers the day, date, year, and where they are. They may have developed a system that is used to review the day and the plan for the day.
  - May still have problems concentrating. Can still get confused if asked to do a new or hard task. They have a hard time planning, starting and completing tasks.
  - Is stronger so can follow a daily schedule easier and do all their self-care tasks.
  - Can interact socially with friend and family as well as the staff. May still have inappropriate talk and behaviors.
  - Can still have emotional ups and downs. They may say if they are feeling wonderful (euphoric) or depressed. Most of the time their facial expressions will match the reported feelings.
  - Does not start activities or conversations as often as before the accident. They will generally respond correctly if given help to get started. (Also known as poor initiation).
May seem cautious or unsure of themselves in a new situation. This is expected as they have just started to remember day to day events.

May or may not understand that the problems they are having are related to the brain injury.

May start expressing worries and have unrealistic ideas for the future. This may be due to denial, as a result of new situations or changing environment. This often happens when they are close to going home or after they have gone home from the hospital.

**Things to work toward during stage 7:**

- Help them to remember day-to-day events. Review with them what happened during the day.
- Help and encourage them to use memory aids on a daily basis.
- Help improve memories of past events – reminisce.
- Help improve ability to think and express ideas – play simple games, talk about events and places they may have attended.
- Look at long term effects of the injury on physical and thinking skills.
- Point out how well they are doing. Give them reminders of what they are still working on.
- Neuropsychological testing helps to determine what will still need to be working on after they go home. This test will help with decision to return to work and driving as well as to know when they can live independently.
- Consider vocational training.
Stage 8: Purposeful / Appropriate:

- Your loved one may experience any of the following regarding thinking skills:
  - Can usually remember what happens day to day.
  - Are able to learn new skills
  - May have only minor problems with new or hard situations
  - May still have minor difficulty with reasoning, judgment and dealing with frustration.
  - May be more likely to “act without thinking” than before the injury.
  - Basic thinking skills have improved. Improvements will continue over time but the changes are slower and less dramatic.
  - Starts to understand that some problems may be permanent or take a long time to improve.
  - Continues to learn ways to do things differently to live with the problems.
- Your loved one may experience any of the following regarding emotions:
  - They may have feelings of depression when thinking about the future
  - They may attempt to do things they are not able to do.
  - They may be fearful and become more dependent on their family or loved ones.
- Your loved one may experience any of the following regarding driving
They usually begin to express more desire to drive. At this stage most people with a brain injury can be released to do modify driving – short distances, during low traffic times etc.

The ability to think quickly and about more than one thing at a time may still be a problem.

They may still have difficulty when driving in a busy city, following complicated directions, or in downtown areas where there are one-way streets.

State laws have rules about when a person with a brain injury can return to driving. The brain injured person must be released by his or her doctor and will need to complete testing to get their driving license renewed.

**Things to work toward during stage 8:**

- **Continue to work on knowing the limitations as a result of the brain injury.** Help your loved one participate in familiar activates, if they struggle, talk to them about the problems and provide reassurance that the brain injury is the cause.

- **Focus on strengths and see how they can be used to improve the future.**

- **Give guidance and assistance with decision making but listen to their opinion and show respect.**

- **Talk to your loved one as an adult, there is no need to use simple words or sentences.**

- **They may not understand humor, as a part of the brain injury, so be careful when teasing.**

- **Work on adjusting to the possibility of permanent limitations.**

- **Focus on vocational rehabilitation if appropriate**
Safety Education

**How to keep your loved one safe when in the hospital:**

Confusion, balance problems and poor judgment is common after a brain injury. This can increase the risk of falling and injury. Nursing and therapy staff will follow safety measures to make sure your loved one is safe while in the hospital to reduce falls and prevent further injury. Changes to your home may need to be made before you are able to bring your loved one home. Many times it may be recommended that family members provide hands on assistance or 24 hour supervision once your loved one goes home because they may not be able to recognize dangerous situations, may have balance/strength problems, or may lack the awareness of their problems related to the brain injury.

**Examples in the hospital:**

If your loved one has attempted to get up without help, nursing and therapy staff may use all or some of the below safety precautions:

- Bed and personal alarms may be used. These will notify staff and family members when your loved one is getting up without assistance.
• A soft belt may be applied to help maintain sitting balance and are used for safety. They are used as a reminder to your loved one to not get up alone.

• Use of an enclosure bed to prevent injury if your loved one is at risk of falling out of bed.

• A high low bed can be positioned close to the floor to lessen injury in case of a fall.

• Use of a walking device (cane, walker, hand held assistance) or a wheelchair if your loved one is unable to walk without help.
• 1:1 Hand off- A staff member will be assigned to stay in the room. Your loved one is never to be left alone!

• Nursing and therapy staff may use lift equipment or a slide board to reduce the risk of falling and injury.
• When out of bed, therapy staff and nursing will use a gait belt (walking) belt to reduce the risk of falling/injury.
• Mitts may be worn on the hands to reduce the chances of tubes (feeding, IV) getting pulled out.

*Family training* will be encouraged before going home. This will include family participation during therapy sessions to learn how to help with walking and stairs, arm and leg strengthening, activities of daily living, communication, memory and increasing safety awareness.
How to keep your loved one safe at home:

Once you have been given the news that you will be able to return to your home, you may have questions about how to ensure that your home is safe. Often even at discharge a person who has experienced a brain injury may still need to have their home set up so that they do not get into a situation that could cause injury.

Examples you can use to increase the safety of your home:

Some or all safety precautions may be recommended to ensure your loved one is safe at home.

Keep walk ways clear in the hallway and on the stairs to reduce the risk of tripping.

- Reduce clutter.
- Remove throw rugs.
- Provide good lighting especially on stairs.
- Use night lights or have a lamp at the bedside to increase visibility and to prevent falls.
- Wear tennis shoes or non-slip socks with walking to prevent slipping.
- Install safety rails on stairs, around tub or toilet - your therapy team will give you direction if this is needed.

Safety proof your home:

- Limit access to potentially dangerous areas such as bathrooms, basement, stairs and medicine cabinets by locking doors or placing a safety gait at the top of the stairs.
- If it has been advised that cooking should be done only with supervision. Turn off the stove when not in use –
some people have installed a key lock system, others turn off the energy source.

- Remove breakable and dangerous items such as matches, power appliances, knives or chemicals (gas, lighter fluid, turpentine etc).
- If your loved one has poor memory and is able to walk, place an identification bracelet on their wrist in case they wander outside and become lost.
- If the rehab team recommends 24 hour supervision, this means that you should always be with your loved one, they should never to be left alone!
- Let your neighbors know your situation so that they can be another set of eyes to help you monitor safety.
- Use an exit alarm to notify you if your loved one is attempting to leave the house. **Example:** Attach a bell to the door.
- Use a mat alarm near the bed or pull tab alarm to alert you if your loved one is attempting to get up alone in the middle of the night (if interested in purchasing these items please let your rehab team know). They can be purchased locally: [http://www.padalarm.com/](http://www.padalarm.com/)
Bedroom safety:
1. Consider using a bedside urinal or commode to reduce risk of falls in the middle of the night.
2. If you sleep with your loved one, move the bed to rest against the wall and sleep so that they will have to crawl over you to get out.
3. Move your room so that the area is open and it is easy to get to the bathroom.

Medicine Safety
1. Keep medicines secured
2. Assist your loved ones with making sure they take medicines correctly.
3. Use a medicine planner to keep track of the medicine schedule.
4. A locked medicine cabinet will help keep the medicines secure.

Move any electrical tools or potentially dangerous equipment and put them in a locked room or box.
If you have guns or any fire arms in your home move them to a different location.
NO DRIVING until approved by your medical doctor. Some people remove the car keys to make sure that their
loved one will not be tempted to drive. It may be necessary to lock the keys at all times.

- If there is a special vehicle the loved one is interested in driving remove it to avoid temptation (such as a motorcycle).

Additional recommendations:

- Use assistive devices (such as tub benches, safety rails around toilets, walkers etc) which were recommended to you by your therapist at the time of discharge from the hospital.
- Attend outpatient Physical, Occupational and Speech therapy as recommended by the healthcare professionals.
- When your loved one is tired after a long day, remember that they will have a slower response time and may not think as clearly as usual. They will move slower and think slower. Plan for rest breaks before meetings and events.
- Always carry identification with emergency contact and medical information. Consider getting a medical alert bracelet or necklace.

The risk of having another brain injury increases after having one Brain Injury. Talk with your doctor and therapy staff first, before resuming contact sports, like:

- Horseback riding
- Swimming
- Hunting
- Using Firearms
- Using power tools or sharp objects
- Riding or driving recreational vehicles
- Cooking without supervision
Common Changes Seen After A Brain Injury

Driving

Driving is an important part of a person’s ability to be self-reliant and to get around. We take our driving skills for granted, and it’s easy to forget that driving is the most dangerous thing we do in our everyday lives. A brain injury can affect the skills needed to drive safely. When a person can safely return to driving should be addressed early in recovery. The injured person, family members, and health professionals should all be included in this important decision. If anyone has concerns that driving may put the injured person or others in danger, then health professionals may advise pre-driving testing be done.

How can a Brain injury affect driving ability?

A Brain Injury can disrupt and slow down skills that are needed for good driving such as:

- Being able to see clearly and in all directions.
- Being able to stay in the correct lane on the road.
- Being able to keep focused over long periods of time.
- Remembering directions and safety rules.
- Thinking quickly about what to do for problems that can come up when driving.
- Hand-eye coordination and being able to judge distances.
- Reaction time - such as breaking in time to prevent an accident.
- Understanding safety rules and knowing what is safe and what is not safe when driving.

Studies show that even mild problems, may add to bigger risks while driving.
Warning signs of unsafe driving:

- Driving too fast/slow.
- Not following signs or signals.
- Judging distance wrong when stopping or turning.
- Slowed decisions making.
- Becoming easily frustrated or confused.
- Having accidents or near misses.
- Drifting across lane markings into other lanes.
- Getting lost easily, even in familiar areas.

How often do individuals with Brain Injury return to driving?

Between 40 and 60 percent of people with moderate to severe brain injury will return to driving at some time. To lessen the risk of crashes, people with brain injury may need to change their driving activity. They may drive less often than they did before the injury. They may also drive only at certain times (such as during daylight), on familiar routes, or when there is less traffic.

Having had a seizure after a brain injury may be a barrier to driving. State Law often requires that a person be free of seizures for 6 months or so, before driving again. People who want to return to driving need to check the laws in their state.

Driving evaluations and training:

A driving evaluation is a key step in deciding if a person is able to drive after a brain injury. Research studies indicate that most brain injury survivors are not thoroughly evaluated for driving skills before they begin driving.

If a Brain Injury survivor starts to drive before they are ready they are at risk for a crash, which could result in a second injury.
While there is no standard assessment, test or process to judge if a person is ready to return to driving, a typical driving evaluation has two parts:

- **Cognitive Evaluation:** A review of cognitive (thinking) skills, including reaction time, judgment, reasoning and visual skills. Recommendations regarding the need for helpful tools and additional training are based on the results of this evaluation.

- **On-the-Road:** A test of the mechanical operation of a vehicle, either using a driving stimulator or driving a vehicle on the roadway with a Certified Driver Rehabilitation Specialist. This evaluation is used to assess safe driving skills in various traffic settings, as well as basic driving skills while the person uses adaptive driving equipment if needed.

Current research indicates that many people with Brain Injury can become good, safe drivers when given the right training. Training helps to improve specific driving skills. Sometimes this involves practicing driving under the supervision of a driving evaluator. In some cases, a training program might focus on specific skills such as rapid understanding of visual information.

Evaluations and training are often provided by professionals certified through the Association for Driver Rehabilitation (ADED). A list of certified professionals may be found on the ADED website, [www.driver-ed.org](http://www.driver-ed.org).
Vehicle modifications:
If a person has physical weaknesses, but has good thinking skills, they may be able to return to driving with adaptive equipment or other changes to the vehicle.

Examples of adaptive equipment that can be added to the vehicle are:

- Hand-controlled gas and brake systems.
- Spinner knobs for steering.
- Left foot accelerator.
- Lifts for entering and exiting the vehicle.

Legal and insurance considerations:
A person who wishes to resume driving must have a valid driver’s license. In some states, there must be a formal evaluation performed by a licensing bureau before resuming driving after a brain injury. Insurance may also be required. The person should check local rules relating to licenses and insurance.
Other transportation options:

Having a way to get to places, such as getting together with family and friends, going out to eat and movies is an important part of life. If a person is not able to drive, there may be other ways to get around. Family members or friends can provide rides. Public transportation such as buses, taxies, or ADA Para-transit services can also be used. ADA Para-transit services provide public transportation especially for disabled riders. Most communities have this service.

Step-by-Step: Should you be driving?

- Discuss your ability to drive with your doctor and/or health specialists and family.
- Get professional testing to find out about your driving ability.
- Based on your evaluation, you may be allowed to drive. However, you may need training or vehicle modification before returning driving. Some persons are told to use other transportation options.

Recommended resources:

- Brain Injury Association of America. www.biausa.org
- State Vocational Rehabilitation Offices. www.jan.wvu.edu
- Association for Driver Rehabilitation Specialists. www.driver-ed.org
- National Mobility Equipment Dealers Association. www.nmeda.org
- ADA Para-transit services. www.publictransportation.org
Brain Injury Education

Common Changes after a Brain Injury

Brain Injury and Fatigue
Brain Injury and Irritability
Brain Injury and Distractibility
Brain Injury and Impulsivity
Brain Injury and Changes in Mood
Brain Injury and Memory Changes
Brain Injury and Sleep Concerns
Brain Injury and Fatigue

**What is it?** Feeling sleepy or tired or having very little energy much of the time. Your loved one may nap and sleep a lot, but less deeply. The need for rest, naps and extra sleep may last a long time after the injury. Remember most everything your loved one does and says take a lot of extra effort due to the damaged brain cells, chemical changes and swelling in the brain. For example, your loved one may have to work extra hard for things that we do without effort like coughing, swallowing, and thinking. Your loved one may also be sleeping poorly, eating and drinking less than they did before, and be sad, which can lower his/her energy level.

**Examples of fatigue in the hospital:**
- Wanting to sleep through therapy.
- Falling asleep when visitors are present.
- Getting days and nights mixed up and sleeping more during the day.

**Examples of fatigue at home:**
- Sleeping a lot of the day.
- Napping often.
- Slowed thought processing and delayed speech/movements when tired.
How to help your loved one with fatigue and low energy:

- Reduce the number of visitors to only 2 or 3 at a time and encourage only one person to speak at a time (do not have multiple conversations at the same time). Conversations should be limited and you should have the TV off.
- Keep visits short. An hour in the hospital is ideal and then limit to only a few hours at a time at home.
- Follow a routine and go to bed about the same time each night.
- Take breaks between tasks and activities; pace activities during the day and week.
- Schedule nap time especially mid-morning and mid-afternoon, or at least after lunch.
- If days and nights are mixed up, keep naps limited to only 30 minutes during the day.
- Don’t leave the TV or radio on all the time, have some quiet times throughout the day and evening.
- Have a protein with a fat for breakfast, not just coffee with caffeine and rolls/doughnuts. A few cereals have higher protein content now, and you can add almond slivers or unsalted sunflower seeds to them. Eggs and milk also have protein.
- Stop drinking caffeinated drinks by 2 PM so they do not keep you awake at night.
- Drink all of your fluids before 7 PM or four hours before you go to bed, so you wake up to go the bathroom less often during the night (a few sips with bedtime pills is ok).
- Celebrate successes no matter how small. Try to do something fun each day.
• Sit up and breathe deeply every so often to get oxygen out of the body parts.
• Give priority to tasks that are important and do them early in the day when you are rested. For example, have him/her do thinking tasks while he/she is fresh, or have visitors/family come after a nap. Have him/her do the hard exercises first and the easy ones when he/she is starting to get tired.
• Avoid spending time and energy on those things that cannot be changed.
• Find positive ways to release pent-up energy and frustrations like listening to music, doing an easy crossword puzzle together, taking a drive, etc.
• Use walkers/wheelchairs to move long distances.
• Use calendars, notebooks, schedules, checklists, timers and computers to make tasks easier.
Brain Injury and Irritability

**What is it?** People with brain injury can have difficulty controlling their emotions, and become angry or upset faster than usual.

- Family members of a person with brain injury often describe the injured person as having a “short fuse,” “flying off the handle” easily, being upset or having a quick temper. Studies show that up to 71% of people with brain injury are frequently irritable.

- The injured person may yell, use bad language, throw objects, slam fists into things, slam doors, or threaten or hurt family members or others.

**Irritability after brain injury is likely caused by many factors, including:**

- Injury to the parts of the brain that control emotions.
- Frustration and dissatisfaction with the changes in life brought on by the injury, such as loss of one’s job and independence.
- Feeling alone, depressed, or misunderstood.
- Trouble concentrating, remembering, expressing oneself or following conversations, all of which can lead to frustration.
- Tiring easily.
- Pain
What are some of the symptoms/behaviors the person may display?

- Following a brain injury, your loved one may be very confused, frightened and may not understand what is happening around them.
- Your loved one may overreact to what they see, hear, or feel by hitting, screaming, using foul language or showing other bad behavior (this is often referred to as agitation). Your loved one may be restrained so that they do not hurt themselves.
- Your loved one may be highly focused on their basic needs; like eating, pain relief, going back to bed, going to the bathroom, or going home.
- Your loved one may not understand that people are trying to help them.
- Your loved one may not pay attention or be able to focus for even a few seconds.
- Your loved one may have trouble following directions.
- Your loved one may need help to do even simple routine things like feeding themself, dressing or talking.
What can be done for your loved one right now about irritability?

- Tell them where they are and assure them that they are safe.
- Bring in family pictures and personal items from home. This will help them feel more comfortable.
- Allow them as much movement as is safe.
- Take them for rides in his wheelchair, with permission from nursing.
- Find familiar tasks that are calming to them; such as listening to music, or eating (make sure it is okay with staff).
- Do not force them to do things. Instead, listen to what they want to do and follow their lead, within safe limits.
- Since they often becomes distracted, restless, or upset, you may need to give them breaks and change tasks often.
- Keep the room quiet and calm. For example, turn off the TV and radio, don't talk too much and use a calm voice.
- Limit the number of visitors to 2 or 3 people at a time.

What can be done about irritability in the long term?

- Reduce stress and decrease irritating situations to remove some of the triggers for temper outbursts and irritability.
• People with brain injury can learn some basic anger management skills such as self-calming thoughts, relaxation and better communication methods. A psychologist or other mental health professional familiar with brain injury can help.

• Certain medicines can be ordered to help control temper outbursts and irritability.

**How you can help by changing the way that you react to irritability:**

• Understand that being irritable and getting angry easily is due to the brain injury. Try not to take it personally.

• Do not try to argue with your loved one during an outburst. Instead, let them cool down for a few minutes first.

• Do not try to calm your loved one down by giving in to their demands. Set some rules for communication. Let them know that it is not okay to yell at, threaten or hurt others. Refuse to talk to them when they are yelling or throwing a temper tantrum.

• After the outburst is over, talk about what might have led to the outburst. Encourage your loved one to discuss the problem in a calm way. Suggest other outlets, such as leaving the room and taking a when they feel anger coming on (they should always let others know when they will return).
If your loved one (or you) are feeling anxiety, sadness or depression, irritability or mood swings, consider asking your doctor or treatment provider:

- Would counseling be helpful?
- Would an evaluation by a psychiatrist be helpful?
- Are there medicines that can help?

**Medicines for emotional concerns**

- If you or your healthy family member tries a medication for one of these problems, it is key to work closely with the doctor or other health care provider who prescribes them. Always make a follow-up appointment to let them know how the medicine is working, and report any unusual reactions between appointments.
- Understand there can be a delay until the beneficial effects of medicines are felt and that not all medicines work the same for everyone.
- Doses might need to be adjusted by your doctor for full benefit.
- Except in an emergency, you should not stop taking a prescribed medicine without talking to your doctor.
Brain Injury and Distractability

**What is it?** The mind wanders and has trouble focusing on one task, activity or conversation long enough to finish it. After brain injury, your loved one may start tasks without finishing them and often times will not notice this behavior. This may happen because of things going on inside the body like pain, fatigue, stress, fear, tension, constipation, etc. It may also happen because of too many things going on around you. For example, there is too much chaos, noise, heat, or too many people and/or electronics on like the TV and radio on. It may also happen after changes in the environment such as furniture rearrangement, varying the daily routine, getting a new pet, etc.

**Examples of distractibility in the hospital:**
- Eating only half a meal.
- Taking only a few pills and leaving the rest.
- Stopping exercises in therapy unless being reminded by therapists to keep going.

**Examples of distractibility at home:**
- Not watching very much of a TV program.
- Emptying part of the dishwasher and leaving the rest of the dishes in it.
- Having to go to the closet or dresser many times to get all of the clothes that they are going to wear.
How to help your loved one with being easily distracted:

- Try to prevent internal problems such as pain, tension, constipation, etc.
- They should get several hours of sleep each night and nap at least after lunch during the day.
- You or other family members may not be able to talk while they are doing a task.
- Your loved one should read their schedule often and may need the schedule to list hour by hour tasks.
- Follow simple directions to do an activity. For example, if your loved one is cooking, they should use short recipes.
- Set a timer to remind your loved one to finish one task before starting another one. They may need to reset it a few times to remind them to keep going.
- Limit noise when doing a task. They may need to turn off the TV, music, or the computer.
- Ask friends and family to speak one at a time and not switch subjects quickly.
- Encourage your loved one to leave a group for a few minutes if there are too many people and too much noise all at once.
- Talk on the phone in a quiet place.
- Shop or eat out when stores are less busy.
- Simplify your routine, activities and home life.
- Remove clutter and organize things to help your loved one find them easily since too much clutter may be distracting.
- Put frequently used items in the same place all the time so they do not have to waste time looking for keys, a pen, their phone, etc.
- Call your loved one to remind them of when they need to leave for a meeting or appointment or to start to make a meal.
- Pace activities and encourage rest in between.
Brain Injury and Impulsivity

What is it? Saying or doing a task quickly and without prior planning or thinking. It may be your loved one saying something “off the top of his/her head” which may seem rude or bold to others. It may also be seen as acting or moving too quickly and unsafely. Sometimes it seems as if the person has little “common sense.”

Examples of impulsivity in the hospital:
- Saying a nurse or therapist is fat or dumb.
- Getting out of bed or a chair alone when they may fall due to being unsteady and weak.
- Bending over to reach for a pen that drops on the floor when poor balance is present.
- Getting up without their helmet.

Examples of impulsivity at home:
- Telling a clerk at a store that they are sexy or telling a friend who brings food as a gift it tastes bad or is too dry or isn’t fit to eat.
- Drinking hot chocolate before it has cooled and it burns the hand so your loved one drops it and breaks the cup.
- Getting into the shower without help and without the rubber bathmat or tub bench in place.
- Walking into the street without looking for traffic.
How to help your loved one who is impulsive:

- Realize it stems from the brain injury and is not being done on purpose.
- Tell close family and friends that your loved one is impulsive so may say or do things quickly and without thinking. Warn them that some comments may be blunt, hurtful or embarrassing.
- Gently point out a comment might be too blunt and rude and model a more polite comment or statement such as “We thank you for the casserole, my husband is used to spicy foods with too much salt, so other foods may taste a bit bland to him.”
- It may not be safe to leave your loved one alone, or to do so for only short periods of time.
- Give gentle reminders before or during an activity such as to get up only with help, or to slow down eating or to take smaller bites so they do not choke.
- Remind your loved one not to touch hot things. Give simple clues like the drink is too hot if it has steam rising.
- Schedule outdoor time together on an actual daily schedule. This will prevent your loved one from going down a step, or walking on broken cement or uneven ground alone or getting too near traffic.
• Plan ahead to keep rooms and areas safe:
  o Turn hot water heater down to 120 degrees
  o Remove throw rugs
  o Keep newspapers and magazines off the floor
  o Pull up the bedspreads so that they do not hang too close to the floor
  o Keep rubber bath mats and bathing equipment dry after being used.
  o Put childproof locks on meds, cupboards and drawers that contain chemicals or sharp objects.
  o Anticipate safety hazards in each room and remove them.
Brain Injury and Changes in Mood

A brain injury can change the way people feel or express emotions. A person with brain injury can have several types of emotional problems.

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

What causes this problem?

- Mood swings and emotional lability are often caused by damage to the part of the brain that controls emotions and behavior.
- Often there is no specific event that triggers a sudden emotional response. This may be confusing for family members who may think they accidentally did something that upset the injured person.
- In some cases the brain injury can cause sudden episodes of crying or laughing. These emotional expressions or outbursts may not have any relationship to the way the persons feels (in other words, they may cry without feeling sad or laugh without feeling happy). In some cases the emotional expression may not match the situation (such as laughing at a sad story). Usually the person cannot control these expressions of emotion.
What can be done about it?

- Fortunately, this situation often improves in the first few months after a brain injury, and people often return to a more normal emotional balance.

- If your loved one is having problems controlling their emotions, it is important to talk to your doctor or psychologist to find out the cause and get help.

- Counseling for you or other member of your family can be reassuring and allow you to cope better on a daily basis.

- Several medicines may help improve or stabilize mood. You should talk to a doctor that is familiar with the emotional problems caused by brain injury.

What family members and others can do.

- Remain calm if an emotional outburst occurs and avoid reacting emotionally yourself.

- Take your loved one to a quiet area to help them calm down and regain control.

- Acknowledge feelings and give your loved one a chance to talk about feelings.

- Provide feedback gently and supportively after your loved one gains control.

- Gently redirect attention to a different topic or activity.
**Anxiety**

Anxiety may be out of proportion to the situation. Your loved one may feel anxious without exactly knowing why. They may worry and become anxious about making too many mistakes, or “failing” at a task. They may feel like they are being criticized. Many situations can be harder to handle after a brain injury and cause anxiety, such as being in crowds, being rushed, or adjusting to sudden changes in the plan.

Some people may have sudden onset of anxiety that can be overwhelming, these are also known as panic attacks. Anxiety may be related to a very stressful situation—sometimes the situation that caused the injury—that gets “replayed” in the person’s mind over and over and interferes with sleep, this is known as post-traumatic stress disorder. Since each form of anxiety calls for a different treatment, anxiety should always be diagnosed by a mental health professional or doctor.

**What causes anxiety after brain injury?**

- Difficulty reasoning and concentrating can make it hard for the person with brain injury to solve problems. This can make your loved one feel overwhelmed, especially if they are being asked to make decisions.

- Anxiety often happens when there are too many demands on your loved one, such as returning to employment too soon after injury. Time pressure can also heighten anxiety.

- Situations that require a lot of attention and information-processing can make your loved one anxious. Examples of such situations include being in a crowded environment, heavy traffic or noisy children.
What can be done about anxiety?

- Try to reduce the environmental demands and unnecessary stresses that may be causing anxiety.

- Provide reassurance to help calm the your loved one and allow them to reduce their feelings of anxiety when they occur.

- Add structured activities into the daily routine, such as exercising, volunteering, church activities or self-help groups.

- Anxiety can be helped by certain meds. Anxiety can be helped by psychotherapy (counseling) from a mental health professional who is familiar with brain injury. Sometimes both medications and counseling can help anxiety.
**Depression**

- Feeling sad is a normal response to the losses and changes a person faces after brain injury. Feelings of sadness, frustration and loss are common after brain injury. These feelings often appear during the later stages of recovery, after the person has become more aware of the long-term situation. If these feelings become overwhelming or interfere with recovery, the person may be suffering from depression.

- Symptoms of depression include feeling sad or worthless, changes in sleep or appetite, difficulty concentrating, withdrawing from others, loss of interest or pleasure in life, lethargy (feeling tired and sluggish), or thoughts of death or suicide.

- Because signs of depression are also symptoms of a brain injury itself, having these symptoms doesn’t necessarily mean the injured person is depressed. The problems are more likely to mean depression if they show up a few months after the injury rather than soon after it.

**How common is depression?**

- Depression is a common problem after brain injury. About half of all people with brain injury are affected by depression within the first year after injury. Even more (nearly two-thirds) are affected within seven years after injury. In the general population, the rate of depression is much lower, affecting fewer than one person in 10 over a one-year period. More than half of the people with TBI who are depressed also have significant anxiety.
What causes depression?

- Physical changes in the brain due to injury. Depression may result from injury to the areas of the brain that control emotions. Changes in the levels of certain natural chemicals in the brain, called neurotransmitters, can cause depression.

- Emotional response to injury. Depression can also arise as your loved one struggles to adjust to temporary or lasting disability, losses or role changes within the family and society.

- Factors unrelated to injury. Some people have a higher risk for depression due to inherited genes, personal or family history, and other influences that were present before the brain injury.

What can be done about depression?

- If your loved one has symptoms of depression, it is important to seek professional help as soon as possible, preferably with a health care provider who is familiar with brain injury. Depression is not a sign of weakness, and it is not anyone’s fault. Depression can be a medical problem, just like high blood pressure or diabetes. Your loved one may not be able to get over depression by simply wishing it away, using more willpower or “toughening up.” It is best to get treatment early to prevent needless suffering and worsening symptoms.

- If you have thoughts of suicide, get help right away. If you have strong thoughts of suicide and a suicide plan, call a local crisis line, 911, the 24-hour National Crisis Hotline at 800-273-8255, or go to an emergency room immediately.

- Certain medications and counseling, or a combination of the two, can help most people who have depression.
Medications

- Antidepressant medicines work by helping to re-balance the natural chemicals (called neurotransmitters) in the brain. Antidepressants are not “addictive”. It is also important to know that even if antidepressants help with depression, they usually do not have to be taken forever. Sometimes a medicine can help re-balance the brain’s chemistry and can eventually be stopped (for example, after 6-12 months). However, everyone’s situation is unique, and both starting and stopping this type of medicine should always be done under a doctor’s supervision.
- In addition to helping with mood, antidepressants can also help with the other symptoms of depression, such as low energy, poor concentration, poor sleep and low appetite. Some antidepressants can also help with anxiety symptoms.
- There are many different types or “classes” of antidepressant medicines. Studies of depression in brain injury have found that some classes may work better than others.
- After starting antidepressants, it can take a few weeks to feel better. Sometimes your doctor will need to change the dose over time or switch to a different medicine if one doesn’t work well enough. In some cases, two different antidepressants can be used together if a single medicine is not effective.
- It is important to take antidepressant medicine every day, even if you are feeling better. Do not stop it abruptly. In most cases, your doctor will recommend taking the medicine for at least several months.
Counseling

- There are many different kinds of psychotherapy and counseling. For people with depression, the most effective types of therapy are those that focus on day-to-day behavior and thinking.

- Many people do best with a combination of approaches, such as antidepressant medicines plus sessions with a trained counselor to work on changing behavior.

Other treatment approaches

- Other approaches such as exercise, acupuncture and biofeedback have been shown to be helpful in treating depression in the general population. Some people with brain injury also find them helpful. A professional specializing in brain injury should be consulted about these treatments. Treating anxiety and pain can also help to reduce depression. Brain injury support groups may be a good source of additional information and support for depression and other challenges following a brain injury.
Brain Injury and Memory Changes

Short Term Memory Loss

What is it? People with brain injury may have trouble learning and remembering new information and events.

- They may have trouble remembering events that happened several weeks or months before the injury (although this often comes back over time).
- They may have trouble remembering things that happen that day.
- People with brain injury are usually able to remember events that happened long ago.

Examples in the hospital:

- They cannot remember what they just did 30 minutes ago in Speech Therapy.
- They cannot remember safety rules such as not getting out of bed without help.

Examples at home:

- Forgetting phone messages or doctor visits.
- Forgetting if they took the morning medicines.
- Going to the store to buy an item and forgetting what they came for once they arrive at the store.
How to help a loved one who has memory problems

- Put together a plan for daily tasks and events.

- Be organized and have a place to keep items that you use every day like television remotes and cell phones.

- Learn to use memory aids such as notebooks, calendars, daily schedules, or computer reminder programs.

- Encourage your loved one to take time and pay close attention when learning or hearing new information. Have them repeat the new information several times during the day.

- Make sure that your loved one gets rest and avoids stress as much as possible.
Brain Injury and Sleep Concerns

Many people who have brain injuries suffer from sleep disturbances. Not sleeping well can increase or worsen depression, anxiety, feeling tired, irritability, and one’s sense of well-being. It can also lead to poor work performance and traffic or workplace accidents. A review of sleep disorder studies and surveys suggest that sleep disorders are three times more common in brain injury patients than people in general. Nearly 60% of people with brain injury have long-term problems with sleep. Women were more likely to be affected than men. Sleep problems are more likely to develop as the person ages.

Sleep problems have been found in people with all types of brain injuries – from mild to severe. Sleep is a complex process that involves many parts of the brain. For this reason, and depending on the site and extent of injury, many different kinds of sleep disturbances can occur after brain injury.
Common sleep disorders

- Insomnia: Trouble falling asleep or staying asleep; or sleep that does not make you feel rested. Insomnia can worsen other problems resulting from brain injury, including behavioral and thinking function. Insomnia makes it harder to learn new things. Insomnia is typically worse right after a brain injury, but often improves as time passes.
- Excessive Daytime Sleepiness: Extreme drowsiness.
- Delayed Sleep Phase Syndrome: Mixed-up sleep patterns.

- Narcolepsy: Falling asleep suddenly and uncontrollably during the day.

Common sleep syndromes

- Restless Leg Syndrome (RLS): The urge to move the legs because they feel uncomfortable, mainly at night or when lying down.
- Bruxism: Grinding or clenching one’s teeth.
- Sleep Apnea: Brief pauses in breathing during sleep. It results in poor oxygen flow to the brain, loud snoring, and frequent awakening.
- Periodic limb movement disorder (PLMD): Movement of legs and arms during sleep.
• Sleepwalking: Walking or doing other tasks while sleeping and not being aware of it.

**Causes of sleep problems**

• Physical and chemical changes: The “internal clock” in the brain controls when people sleep and wake every day. If injured, the brain may not be able to tell the body to fall asleep or wake up. There are chemicals in our body that help us to sleep. An injury can change the way these chemicals affect the body. If brain processes for starting and stopping sleep are injured, traumatic hypersomnia may result in which a person sleeps much more than normal.

• Changes in breathing control: Sometimes the brain’s ability to control breathing during sleep changes after a brain injury. This results in periods of apnea (when breathing actually stops for long enough for blood oxygen levels to drop). This is called sleep apnea. Other factors may affect the chance of having sleep apnea such as family history or being overweight.

• Medicines: Medicines taken after a brain injury may cause problems going to sleep or staying asleep. They can make people sleepy during the day and unable to join activities.

• Prescription drugs for treating asthma and depression may cause insomnia. Also, stimulants that are meant to treat daytime sleepiness can cause insomnia if taken too close to bedtime. These problems can often be avoided by adjusting the timing of the medication—or by switching to a different one—after talking to your doctor. Many other medicines can cause sleepiness as well.
Most over-the-counter sleep aid medicines contain an antihistamine (commonly diphenhydramine) and are not used for people with brain injury because they may cause problems with memory and new learning. Retention of urine, dry mouth, nighttime falls and constipation are all possible side effects of these medicines.

- **Daytime sleeping (napping) and physical inactivity:** Napping during the day is likely to disturb sleep at night. Inactivity or lack of exercise can also worsen sleep.
- **Pain:** Many people who have suffered brain injuries also have pain in other parts of the body. This discomfort may disturb sleep. Medicines taken to relieve pain may also affect sleep.
- **Depression:** Depression is much more common in persons with brain injury than in the general population. Sleep problems such as difficulty falling asleep and early morning waking are common with depression.
- **Alcohol:** While alcohol may help bring on sleep, drinking alcohol before bedtime is likely to interfere with normal sleep rather than improve it.
- **Caffeine and Nicotine:** Nicotine from tobacco may cause sleep problems and is often overlooked. Caffeine can disturb sleep when drank in the afternoon or evening.
Improving sleep

Daytime suggestions

- Set an alarm to try to wake up at the same time every day. Include meaningful activities in your daily schedule.
- Get off the couch and limit TV watching.
- Exercise every day. People with brain injury who exercise regularly report fewer sleep problems.
- Try to get outdoors for some sunlight during the daytime. If you live in an area with less sun in the wintertime, consider trying light box therapy.
- Don’t nap more than 20 minutes during the day.

Nighttime suggestions

- Go to bed at the same time every night and set your alarm for the next day.
- Follow a bedtime routine. For example, put out your clothes for morning and brush your teeth. Then read or listen to relaxing music for 10 minutes before turning out the light.
- Do not drink caffeine, nicotine, alcohol and sugar for five hours before bedtime.
- Do not eat prior to going to sleep to allow time to digest. Do not go to bed hungry, as this can wake you from sleep.
- Do not exercise within two hours of bedtime but stretching or meditation may help with sleep.
- Do not eat, read or watch TV while in bed.
- Keep stress out of the bedroom. For example, do not work or pay bills there.
- Create a restful feeling in the bedroom, away from distractions, noise, extreme temperatures and light.
If you do not fall asleep within 30 minutes of going to bed, get out of bed and do something relaxing or boring until you feel sleepy.

**Treatment options**

- Talk to your doctor if your sleep problems persist.
- If mood or emotional issues such as anxiety or depression are causing sleep difficulties counseling may be helpful.
- Sleep restriction may improve sleeping patterns by limiting the number of hours spent in bed to the actual number of hours slept.
- For those with anxiety, relaxation therapy can help create restfulness in your bedroom and in your body and mind.
- Use of special bright lights (phototherapy) has been shown in studies to help promote sleep. By using these lights at strategic times in the day, you may be able to sleep more at night. However, consult with your doctor first, as these bright lights can cause eyestrain and headaches.
- Medicines: Ask your doctor about medicines that can help you sleep through the night or keep you awake during the day. Special care is needed when choosing a medicine to avoid daytime sleepiness or worsening of cognitive and behavior problems.
- Natural remedies: Some people have found herbal teas, melatonin and valerian useful for sleep problems. You should talk to your doctor before using these.
What is a seizure? A seizure occurs because of abnormal electrical activity in the brain. Seizures sometimes occur after brain injury and they interrupt nerve impulses in the brain. People having a seizure may go unconscious or lose awareness of what is going on around them. They may not understand what is being said to them during a seizure. A person is most likely to have a seizure within 6 months of a brain injury; however, seizures could occur up to two years afterwards.

What does a seizure look like? There are several types of seizures. In one type of seizure, the person suddenly goes unconscious and then the body goes stiff and then begins to jerk. Another type of seizure occurs in which the person stays conscious, but briefly stops talking, and stops the activity they were doing at the time of the seizure. They may look like they are staring into space and not paying attention to things going on around them. After a seizure your loved one will likely be tired and will need to nap, and they may be confused, weak and sweaty.

Examples in the hospital:
- Often times the jerking type of seizure starts in the face or arms and spreads to the rest of the body. The muscles tighten then relax, and this happens over and over. The person can be asleep, or awake, in a chair, in the gym or
anywhere, when a seizure starts. A bladder accident and drooling of saliva from the mouth may happen also. The seizure may last a few seconds or it may last several minutes. If you think that your loved one is having a seizure, you should get help right away.

- The other type of seizure isn’t as obvious. Instead, the person having the seizure may just pause when talking or stop doing an activity such as brushing their hair, talking or taking a drink. The person may stare, grimace, blink, roll their eyes, smack their lips or chew (even though no food is in the mouth). These actions may last up to 15 seconds, and occur a few times a minute. The person is unaware that this happens and may not remember finishing a task, or a conversation.

Examples at home:

- Your loved one will have the same signs as explained above.
- Your loved one may notice that they have signs right before the seizure occurs and this is called an aura. For example they may have a metal like taste in the mouth, or smell a bad odor.
- A seizure may occur while cooking, driving, watching TV, studying or sleeping etc.

How to help with a seizure:

- Keep your loved one safe during a seizure. If they start to fall, help lower the body to the ground and protect the head. Turn them onto their side to help prevent them from choking.
• Move aside furniture, computers, phones, or anything that might be in the way of their moving arms or legs. Place a towel or shirt under the head or place it in your lap to protect it.
• Stay with your loved one during the seizure. Loosen any tight clothing. **DON’T place your hand or any objects in a seizing person’s mouth.**
• Gently reassure your loved one and tell them what happened after the seizure.
• If your loved one will let you, clean them up and change pants if wet from urine. Sometimes the person is too tired or grumpy and only wants to sleep.
• Help your loved one into a comfortable place so they can sleep after the seizure; this is how the brain recovers.

**How to prevent seizures:**

• Take seizure medicines at about the same time every day. Don’t stop taking the medicines for seizures unless your doctor tells you to. Your doctor will tell you exactly how to take the medicine.
• When the medicine is stopped, most times your doctor will gradually decrease the medication. For example, the doctor may have you lower the dose a little bit every few days so your body has time to adjust to less medicine.
Do not take over the counter medicines, street drugs, and herbs unless you have talked to your doctor about taking them. Many of these may lessen the effects of the anti-seizure medicine and make you more prone to having seizures.

Make sure your loved one gets plenty of sleep and sleeps about the same number of hours each night.

Do not drink alcohol or caffeine since they can both lessen the effect of medicines that are used to prevent seizures.

Reduce the stress level.

Make sure your loved one is eating a healthy, balanced diet each day.

Stay away from flashing lights, or other factors known to trigger seizures.

Call your doctor if your loved one has the flu and can not keep the anti-seizure medicine down.

If diabetic, prevent hypoglycemia (low blood sugars) since that too might make your loved one more likely to have a seizure.

Do not drive. Your loved one may not be allowed to drive until they are seizure free for a year (Check with your state laws about this).

Do not operate heavy or dangerous equipment until being seizure free for a year.

Do not swim or take a bath alone until your medicine is controlling the seizures very well, so that there is no chance of having a seizure and drowning.
Alcohol and Brain Injury

After a brain injury, many people notice their brains are more sensitive to alcohol. Drinking increases your chances of getting injured again, makes thinking problems worse, and increases your chances of having emotional problems such as depression. In addition, drinking can reduce brain injury recovery. For these reasons, staying away from alcohol is strongly recommended to avoid further injury to the brain and to promote as much healing as possible.

**Alcohol and brain injury recovery**

- Alcohol slows down or stops brain injury recovery.

- Not drinking is one way to give the brain the best chance to heal.

- People’s lives often continue to improve many years after brain injury.

- Not drinking will increase the chance of improvement.
Alcohol, brain injury, and seizures

- A traumatic brain injury puts your loved one at risk for developing seizures.

- Drinking alcohol may cause your loved one to have a higher chance of having a seizure.

- Not drinking can lower the chance of developing seizures.

Alcohol and the risk of having another brain injury

- After a brain injury, survivors are at higher risk (3 to 8 times higher) of having another brain injury.

- Drinking alcohol puts survivors at an even higher risk of having a second brain injury. This may be because both brain injury and alcohol can affect coordination and balance.

- Not drinking can lower the chances of having another brain injury.

Alcohol and mental functioning

- Alcohol and brain injury have similar negative effects on mental abilities like memory and thinking flexibility.

- Alcohol makes some of the thinking problems caused by brain injury to be worse

- Alcohol may affect your loved one more than it did before their injury.

- The negative mental effects of alcohol can last from days to weeks after drinking stops.
• Not drinking is one way to keep your mental abilities at their best and stay sharp and focused.

**How much alcohol is “safe” after a brain injury?**

• After a brain injury the brain is more sensitive to alcohol. This means that even one or two drinks may not be safe, especially when you need to do things that require balance, coordination and quick reactions, such as walking on uneven surfaces, riding a bicycle or driving a car. The fact is, there is no safe level of alcohol use after a brain injury.

![No drinking symbol]

**Alcohol and medications**

• Alcohol is especially dangerous after a brain injury if you are taking certain prescription medications. Alcohol can make some medicines less effective and can greatly increase the effects of others, potentially leading to overdose and death. Using alcohol along with anti-anxiety medications or pain medications can be highly dangerous because of the possible multiplying effect.

**What about using other drugs?**

• Alcohol is a drug. Almost everything mentioned above about alcohol applies equally to other drugs. If your drug of choice is something other than alcohol—such as marijuana, cocaine, methamphetamine or prescription drugs, anti-anxiety medications
(benzodiazepines such as Ativan, Valium, or Xanax), or pain medication (opioids like Percocet, Oxycodone or Oxycontin)—many of the same principles apply. In addition, use of illegal drugs or misuse of prescription drugs can lead to legal problems. If you use multiple drugs like alcohol and marijuana, or alcohol and pain pills, there is a higher risk of addiction and overdose. Using alcohol and pain medications together, or alcohol and anti-anxiety medications, has killed many people. Contact your doctor if you are drinking and using prescription drugs.
What to do if your loved one begins to abuse drugs or alcohol after a brain injury?

- The stakes are higher when people choose to use alcohol after having a brain injury. Some people continue drinking after a brain injury and don’t have any desire to change that behavior. Others know they probably should stop or reduce alcohol use, but don’t know how or have tried in the past and not been successful. There are many ways to stop using alcohol or other drugs and many ways to reduce the potential for harm. The great majority of people who have stopped having alcohol problems did it on their own. They got no professional help or counseling and did not use Alcoholics Anonymous (AA). Don’t underestimate your ability to change if you want to.

- The key ingredients to changing your drinking are:
  - find people who will support your efforts to change your drinking
  - set a specific goal
  - make clear how you will meet your goal;
  - identify situations or emotions that can trigger drinking, and figure out ways to cope with those triggers ahead of time
  - find a way to reward yourself for sticking to your plan and meeting your goals. If you have questions or concerns about
your drinking, there are many ways to get information or help:

- Take a confidential on-line drinking assessment:  
  http://www.alcoholscreening.org

- Talk to your physician about your concerns, and ask about medications that can help you resist relapse or reduce cravings for alcohol, such as naltrexone (Revia).

- Psychologists or other counselors in your brain injury rehabilitation program can help you get started on a treatment program that is right for you.

- Treatment programs that are available include:
  - Alcoholics Anonymous (AA) has helped millions of people. There are meetings in most towns and cities (http://www.aa.org/).
  - Moderation Management (http://www.moderation.org)
  - SmartRecovery (http://www.smartrecovery.org/)
Brain Injury and Sexual Health

A change in sexual function is common after a brain injury. If your loved one is experiencing sexual problems, there are things you can do to help decrease these problems. Some common sexual problems are listed below

- **Decreased Desire:** Many people may have less desire or interest in sex.

- **Increased Desire:** Some people have increased interest in sex after a brain injury and may want to have sex more often than usual. Others may have difficulty controlling their sexual behavior. They may make inappropriate sexual comments or have inappropriate sexual behaviors.

- **Decreased Arousal:** Many people have difficulty becoming sexually aroused. This means that they may be interested in sex, but their bodies do not respond. Men may have difficulty getting or keeping an erection. Women may have less moisture in the vagina.

- **Difficulty or Inability to Reach Orgasm Climax:** Both men and women may have difficulty reaching orgasm or climax. They may not feel physically satisfied after sexual activity.

- **Reproductive Changes:** Women may experience irregular menstrual cycles or periods. Sometimes, periods may not occur for weeks or months after injury. They may also have trouble getting pregnant. Men may have decreased sperm production and may have difficulty getting a woman pregnant.
What Causes The Changes?

- **Damage to the Brain**: Changes in sexual functioning may be caused by damage to the parts of the brain that control sexual functioning.
- **Hormonal Changes**: Damage to the brain can affect the production of hormones, like testosterone, progesterone, and estrogen. These changes in hormones affect sexual functioning.
- **Side Effects of Medicine**: Many medicines commonly used have negative side effects on sexual functioning.
- **Tiredness**: Your loved one may tire very easily (known as fatigue). Feeling tired, physically or mentally, can affect your interest in sex and sexual activity.
- **Problems with Movement**: Tightness of muscles (known as spasticity), physical pain, weakness, slowed or uncoordinated movements, and balance problems may make it difficult to have sex.
- **Self-Esteem Problems**: Your loved one may feel less confident and attractive after a brain injury. This can affect their comfort with sexual activity.
- **Changes in Thinking Abilities**: Difficulty with attention, memory, communication, planning ahead, reasoning, and imagining can also affect sexual functioning.
- **Emotional Changes**: Your loved one may feel sad, nervous, or grumpy. These feelings may have a negative effect on their sexual functioning, especially their desire for sex.
- **Changes in Relationships and Social Activities**: Some people lose relationships after a brain injury or may have trouble meeting new people. This makes it hard to find a sexual partner.
What can be done to improve sexual functioning?

• Talk with your doctor, nurse practitioner, or other health or rehab professional about the problem. They can help you find solutions. Some people may feel embarrassed talking openly about sexual issues. It may help to keep in mind that sexuality is a normal part of human functioning. Problems with sexuality can be addressed just like any other medical problem. If you are not comfortable discussing sexual problems with your doctor, it is wise to find a health professional who you do feel comfortable talking with.

• Get a medical exam. Make sure you discuss with your provider what medicines you are taking. Women should get a gynecology exam and men may need a urology exam. Ask your doctor to check your hormone levels.

• Consider counseling to help with emotional issues that can affect sexual functioning.

• Life after a brain injury can put stress on your intimate relationship. If you and your partner are having such problems, consider marital or couples therapy.

• Consider starting sex therapy. A sex therapist is an expert who helps people to overcome sexual problems and improve sexual functioning. You can search for a certified sex therapist in your geographic area on the following web-site: http://www.aasect.org/

• Talk with your partner and plan sexual activities during the time of day when you are less tired.

• When having sex, position yourself so you can move without being in pain or off balance. This may mean having sex in a different way or unfamiliar position. Discuss this with your partner.
• Arrange things so that you will be less distracted during sex. For example, be in a quiet place without background noise, such as TV.

• If you have trouble becoming sexually aroused, it may help to watch movies or read books/magazines with erotic images and other sexual content. There are sexual aids developed to help people with disability. A good website for these aids is: www.Myleasure.com/education/disabilty/index.asp

• Increasing your social network can increase your chance to form intimate relationships. You may consider joining a club or other social activities.

**Importance of safe sex**

• Do research to help figure out what method of birth control is safe for you. Remember to protect yourself from sexually transmitted disease are best for you. The following website has some helpful information: http://www.plannedparenthood.org

• Because of changes in thinking abilities, it may be harder for you to remember to use protection or to remember to take it with you.

• You can plan ahead by always carrying a condom or other method of protecting yourself and your partner.

• For women who use birth control pills, or a device that must be replaced, using a calendar or alarm on a smart phone can help you remember to take the pills or change the device.
Bibliography:

References:
Brain Injury Survivals Kit: 365 Tips, Tools and Tricks to Deal with Cognitive Function Loss: Demos Health Publishing, 11 West 42nd Street, 15th Floor, New York, NY 10036, Ph# (212) 683-0072

TBI Model Systems in collaboration with the Model Systems Knowledge Translation Center (http://msktc.washington.edu) with funding from the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education, grant no. H133A060070.


Web Sites:
Brain Injury Association of America. www.biausa.org
State Vocational Rehabilitation Offices. www.jan.wvu.edu
Association for Driver Rehabilitation Specialists. www.driver-ed.org
National Mobility Equipment Dealers Association. www.nmeda.com
ADA Paratransit services. www.publictransportation.org
RANCHO LOS AMIGOS NATIONAL REHABILITATION CENTER
www.rancho.org/research/bi_cognition.pdf
Rancho Los Amigos Foundation www.ranchofoundation.org
http://www.padalarm.com/
http://www.bing.com/images/search