



Understanding Brain Injury

SANFORD
HEALTH

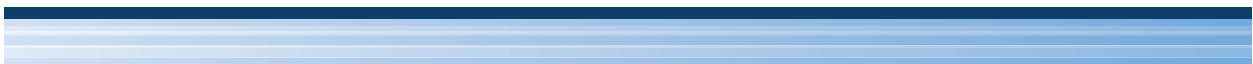


Table of Contents

Welcome	4
About Brain Injury	7
Tests and Procedures	11
Critical Care	13
Stages in Recovery	16
Medical Complications	22
Medications	25
Coping with New Challenges	26
Safety	39
Health and Wellness	42
Preparing for Discharge or Transition	45
Resources	47
Suggested Websites and Reading	52
Helpful Terms	54
Notes	57

Welcome

This book has been written for patients who have had a brain injury and their families. You may have many questions about what will happen as a result of the brain injury. We want to help you learn and be involved in the plan of care. Please ask questions.

This book is to help you understand the nature and treatment of a brain injury.

Updates

It is helpful to choose one person to be the contact and give updates to family and friends.

The Brain Injury Health Care Team

The Patient

The patient is the most important member of the team.

The Family

You are a vital part of the health care team. You can:

- Support the patient and their goals
- Give information about pre-injury health and needs
- Journal if that is helpful for you
- Read, learn, and help your loved one

The Caregivers

You will meet a lot of caring professionals. Each person will introduce themselves and tell you what they do. There is space at the end of this guide that can be used to write names and the roles of these experts if you would like.

Many experts care for people with brain injuries. The care team has doctors, advanced practice providers and nurses. Other members of the team may include:

The **Case Management** team has an RN case manager and a social worker. They help give support to the patient and family. Together, they will work on a discharge plan. They have resources to find answers to financial or insurance questions.

Spiritual Care helps with spiritual support and links to others as you request.

Respiratory Therapists help with breathing problems.

Occupational Therapists focus on moving, thinking, emotional skills, and senses. These skills help the patient to do daily self-care tasks, return to work, and leisure activities.

Physical Therapists are experts who provide treatments to promote movement, reduce pain, restore function, and prevent disability.

Speech Therapists are experts in not only speech and language but also swallowing problems.

Therapeutic Recreation Specialists help the person find ways to relax. They focus on learning leisure activities that the patient is able to do.

Dietitians help find the best foods for healing. Some food choices are based on what the patient can safely take in.

Advice for Families and Loved Ones

Family and friends will be able to visit, but visits may be limited. Visiting a patient who is not able to talk or respond may be hard. Studies show that the person is often still able to hear. When you visit, act and speak as if the person is able to hear you. It may feel odd to talk to someone who seems to be sleeping, but patients often respond best to people they know.

You will spend a lot of time and energy caring for and thinking about your loved one. Families of former patients have offered these tips to help you cope with the stress:

- Get a notebook. Write down questions as they come to mind. Ask the doctor or nurse. Then write down the answers so you can share them with others.
- Keep family and friends updated. You will need their support. Here are some ways to share what is happening:
 - Set up a group text message or email.
 - Leave a message on your voicemail with updates about your loved one.
 - Create an online journal such as Caring Bridge. www.caringbridge.org
 - Create a private social media group page
- Seek out support from:
 - Family and friends
 - Church and/or chaplain services
 - Head injury support groups
- Allow yourself to get away. Take a walk. Invite friends or family members to join you.

Many people will want to help but are unsure how. Here are some ideas:

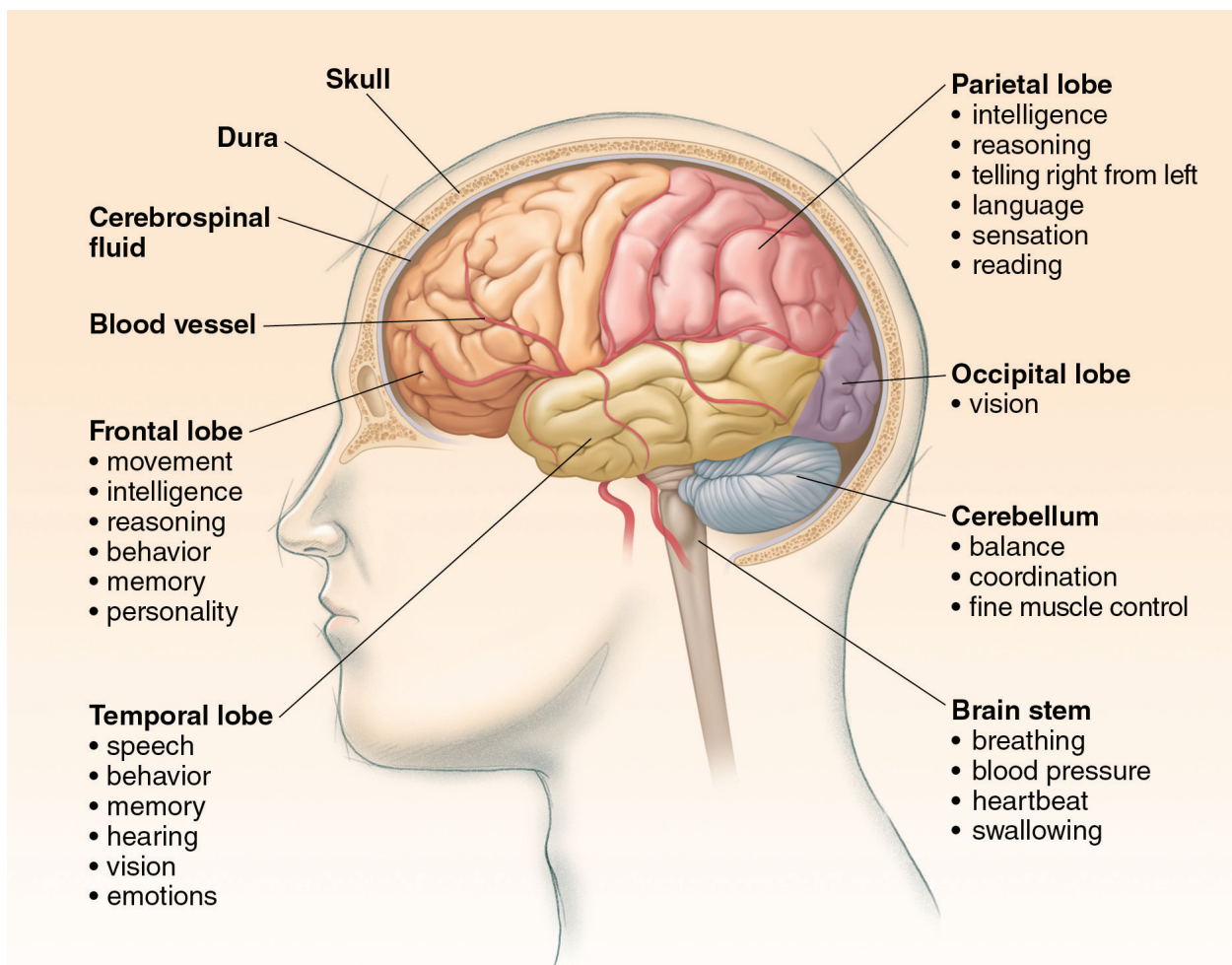
- Ask a family member to be the contact person to take calls and give updates.
- Ask a family member to file and organize medical papers and bills, insurance statements, rehabilitation information, and any other paperwork.
- Let friends and others give food, transport visitors, and help with children as needed.

About Brain Injury

How the Brain Works

Different parts of the brain have different functions:

- **The front of the brain** is the center for emotions and reasoning. This is where most of your personality comes from. Your memory is mainly stored on the sides of the brain, in the temporal lobes.
- **The right side of your brain** controls the left side of your body. The right side also controls problem-solving and skills such as judging distance and recognizing faces.
- **The left side of your brain** controls the right side of your body. It handles most of your speech and language skills.
- **The brain stem** handles basic body functions such as breathing, blood flow, and swallowing.
- **The back of your brain** controls vision.
- **The cerebellum** controls posture, balance, and coordination.



Protecting the brain

There are 3 layers of tissue called meninges that help protect the brain:

- The outer covering of tissue (called the **dura mater**), closely lines the inside of the skull.
- The second layer is the **arachnoid mater**. It holds the other two layers together like a web.
- The third layer, the **pia mater**, hugs the surface of the brain.

The brain is cushioned and supported by a special fluid called **cerebrospinal fluid (CSF)**. This fluid fills the subarachnoid space between the arachnoid mater and the pia mater. Arteries and veins carry blood to and from the brain. Brain tissue will quickly die without a fresh supply of blood.

Causes of Brain Injury

There are 2 types of brain injury: traumatic and acquired.

Traumatic brain injuries can be from:

- Traffic accidents
- Assaults
- Penetrating or open head injuries
- Falls
- Sports injuries
- Concussions

Non-Traumatic (Acquired) brain injuries can be from:

- Stroke or tumor
- Hypoxia (lack of oxygen)
- Meningitis (inflammation of the outside of the brain tissue)

Degenerative brain injuries such as dementia, multiple sclerosis, or Parkinson's disease are not classified as acquired brain injuries. Brain injuries present at birth (congenital) may or may not be considered acquired depending on the source of information.

Traumatic Brain Injuries

Types of traumatic injuries:

- **Concussion** – A concussion is caused by a direct blow to the head or body. This may not show up on any type of medical test. A person may or may not experience a loss of consciousness.
- **Open** – The skull is fractured (broken) with an opening causing the brain to be exposed.
- **Closed** – There may be a skull fracture but there is no opening. The brain remains covered by the skull. This is the most common type of brain injury.
- **Bleeding Inside the Skull (also called a hemorrhage)**
 - The brain has a very large blood supply.
 - Blood vessels are broken or torn when the head is injured.
 - Blood vessels called arteries have a higher pressure inside them. When they tear, they can bleed very fast.
 - A blood clot can form. This is called a hematoma.
 - The clot can push on the brain.
 - Surgery may be needed to remove the clot.
 - Types of bleeding in brain
 - Epidural – Bleeding between the skull and the dural lining
 - Subdural – Bleeding under the lining outside the brain
 - Intracerebral – Bleeding into the brain
 - Subarachnoid – Bleeding around the brain
- **Swelling of the Brain Tissue**
 - This is called brain edema or cerebral edema.
 - Most of the swelling will happen 24 to 72 hours after the brain is injured.
 - The swelling can compress important brain stem centers.
 - The amount of Intracranial Pressures (ICP) in the brain must be kept at normal levels to prevent further brain injury.
- **Diffuse Axonal** – Diffuse axonal injuries can be caused by suddenly moving the head forward and backward. Injury happens when the brain does not keep up with the movement of the skull. This can cause the body's own chemicals to be released in the brain causing further injury.
- **Recurrent Traumatic Brain Injury** – Repeated traumatic brain injury can lead to second impact syndrome (SIS). SIS can be a very dangerous and life threatening condition.

Non-Traumatic Brain Injuries (Acquired)

Non-traumatic brain injuries are the result of non-violent causes. Some of the more common sources are:

- **Stroke** – Also known as a cerebrovascular accident (CVA) or a “brain attack.” A stroke is damage to brain cells caused by a lack of blood flow to the brain.
- **Brain Aneurysm** – Also known as a cerebral or intracranial aneurysm. An aneurysm is an abnormal bulging of an artery in the brain. Should the aneurysm rupture, damage to the brain may occur.
- **Brain Tumor** – Damage to the brain may be caused by the tumor itself or by the surgery, chemotherapy, or radiation.
- **Hypoxia** – A reduction or inadequate flow of oxygen to the brain. Causes may include a heart attack or near drowning.
- **Anoxia** – A total lack of oxygen to the brain. Causes may include heart attack or near drowning.
- **Toxic or Metabolic Injury** – Injury resulting from exposure to something toxic such as:
 - Chemicals
 - High doses of lead
 - Alcohol
 - Drug abuse
 - Carbon monoxide
 - Kidney failure can also result in the build-up of harmful toxins in the brain.
- **Infection** – Bacterial or viral infections may cause:
 - Encephalitis – inflammation or swelling of the brain
 - Meningitis – inflammation of the outside of the brain tissue

How often does brain injury occur?

- In 2015, at least 5.3 million Americans were living with disabilities related to a serious traumatic brain injury (TBI).
- Of all the people in the U.S. who die from an injury, about 1 out of 3 dies from an injury that involved a traumatic brain injury.
- TBIs are the leading cause of death and disability in people younger than 45.

Source:

http://www.acl.gov/Get_Help/BrainHealth/docs/Brain-Health-Brochure-2015.pdf

For the most current information search brain injury statistics at www.nih.gov or www.cdc.gov

Tests and Procedures

Your doctor may order some of these tests or procedures. They will help to know:

- The type of brain injury
- How severe the brain injury is
- How the recovery from the brain injury is going
- How to plan for further treatment

Brain Scan

This is also called a **Cat Scan** or CT.

- It uses a special x-ray machine with a tube. The tube moves in a large circle taking pictures around the patient.
- The patient will need to lie still while the pictures are being taken.
- It creates pictures that are more detailed than a normal x-ray.

Magnetic Resonance Imaging (MRI)

This test uses a special machine that uses magnetic waves instead of x-rays to create pictures of the inside of the body.

- The patient will need to lie still while the pictures are being taken.
- The patient may not wear anything metal while having a MRI. The machine is a giant magnet and attracts metal.
- The machine makes a knocking sound when it is creating the pictures.

Electroencephalogram (EEG)

This test records electrical activity in the brain.

- A technologist measures and marks the patient's head.
- Electrodes are attached to each mark with a strong smelling glue.
- Wires attach the electrodes to the EEG machine.
- The results of this test are looked at by a neurologist.

Cerebral Angiogram

This test provides an image of the blood vessels in the brain. It is used to look for blockage or abnormal blood vessels.

- A doctor numbs the skin.
- The doctor then places a thin tube (catheter) into an artery in the groin or arm.
- The tube is passed up to the blood vessels in the brain. Dye is injected.
- The patient will need to lie still while pictures are being taken.

Transcranial Doppler (TCD)

This test measures how fast blood flows through the brain's blood vessels.

It is used to look for blocked or narrowed blood vessels.

- A probe is placed on the side of the patient's head.
- Ultrasound waves measure the speed of blood flow.
- The patient will need to lie or sit still and not talk.

Spinal Tap

This removes a small amount of spinal fluid from the lower back. Pressure can also be measured.

- The patient will sit up or lie on their side for the procedure.
- The lower back area will be numbed and a needle will be placed.
- A small amount of spinal fluid will be removed and sent for testing.
- The patient will need to lie or sit still and not talk.

Swallow Study

Tests are done to see if there are problems with swallowing. These could be done at the bedside or in the x-ray department.

Neuropsychological Evaluation

Testing may be done during the hospital stay but is often done after discharge.

It can include an interview and paper and pencil tests. This evaluation is used to assist with returning to school, work, or other activities. It measures:

- Attention span
- Memory
- Language and speech skills
- Ability to solve problems

Critical Care (Intensive Care Unit)

Admission to critical care may be needed. The critical care team uses special equipment, medications, and procedures. The goals are:

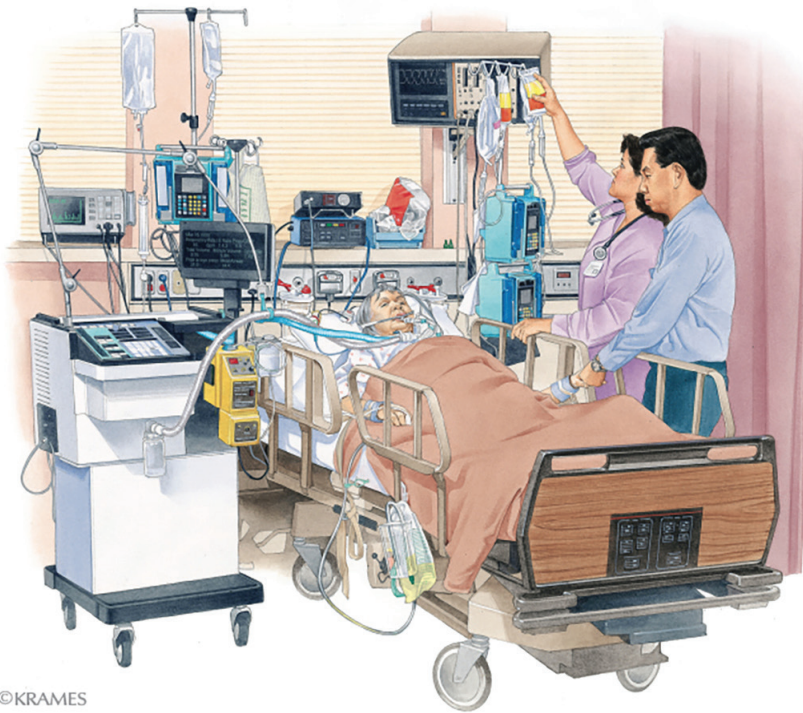
- To make sure the brain is getting enough oxygen and blood
- To control brain pressure and swelling
- To keep the brain as quiet as possible to allow it to heal

Most patients with a brain injury look like they are sleeping. Their eyes are closed and they do not move or talk. Doctors and nurses use a neuro assessment which includes the **Glasgow Coma Scale** (GCS) to track the patient's ability to respond. This scale looks at eye, verbal, and motor (movement) responses. This will help the team decide how well the patient is doing and what care or tests are needed.

Critical Care is a strange place to many people. There are machines and noises that may cause you to feel anxious. You will have many questions. Please ask. Some questions will be hard to answer and may take time:

- How much harm was done to the brain?
- Will the person wake up?
- Will the person be like they were before this happened?
- Will they be able to come home?
- Will they be able to go back to work?

Some patients wake up while in critical care. Others may not. When critical care is no longer needed, the patient will move to another nursing unit.



©KRAMES

Tubes and Equipment

There are tubes and equipment used to monitor a person with a brain injury. These may help avoid problems and assist with care. Some of the tubes and equipment that may be used are described below:

Arterial (Art) line	A thin plastic tube placed in an artery used to measure blood pressure (BP). Blood for lab tests may be drawn from this line.
Central line	An IV placed into the upper chest or neck. It can be used to give fluids, measure pressures, and take blood for testing.
Chest tubes	A tube placed into the side of the chest that helps lungs expand.
Compression stockings or inflatable sleeves	Tight stockings or plastic sleeves that fill and deflate with air and are used to help prevent blood clots.
Cooling equipment	A fan, cooling blanket, or tube placed into a vein that lowers the body temperature (hypothermia). This lessens the body's need for oxygen and energy.
Endotracheal (ET) tube	A tube placed through the mouth into the windpipe (trachea). It is connected to a ventilator that helps the patient breathe.

External Ventricular Drain (EVD)	A thin tube placed into the brain to drain cerebrospinal fluid (CSF). The device also measures pressure in the brain.
Foley (urinary) catheter	A rubber tube placed into the bladder to drain and measure urine.
Gastric tube	A tube placed through the nose (NG) or mouth (OG) into the stomach. This tube drains stomach juices. Later, it may be used to give medicine or liquid food.
Heart monitor	A machine that checks the heart via small patches placed on the body. A heart monitor may look like a TV screen. It shows the heart rhythm (EKG), blood pressure, and other information.
Intracranial Pressure (ICP) Monitor	A thin tube placed through a small hole in the skull into the brain tissue. It is used to measure the pressure inside the brain and drain extra cerebral spinal fluid (CSF) if needed.
Intravenous (IV) line	A thin plastic tube placed into a vein to give medicines, fluids, and blood products. The IV is run by a pump that gives a certain amount of fluid or medicine in a given amount of time.
Oximeter	A small clamp or band aid placed on a finger, toe, or earlobe that measures the amount of oxygen in the blood.
Oxygen	Oxygen may be given through a facemask, nasal cannula (tubing that goes in the nose), or a ventilator.
Partial pressure of oxygen (PbtO ₂) monitor	A thin tube placed through a small hole in the skull into the brain tissue. It records oxygen and temperature levels in the brain.
Tracheostomy	A surgical opening made in the front of the throat into the windpipe (trachea). A tube called a trach is placed into the opening and helps with breathing.
Ventilator	A machine attached to an ET or trach tube that helps the person breathe by pushing oxygen into the lungs.

Stages of Recovery

Care planning will be a constant process between the healthcare team, loved ones, and the patient. When it is time to leave the hospital, some people will be able to return home.

Others may need to continue their recovery in a skilled nursing facility or inpatient rehab unit. This will depend on the injury itself and other health conditions.

When recovery is not expected, palliative (PAL-ee-a-tiv) care can be offered. The main goal of palliative care is comfort.

Revised Rancho Los Amigos Scale

The Revised Rancho Los Amigos Scale is used to measure:

- Level of alertness
- Ability to react
- Progress of recovery

There are two versions of this scale, one with 8 levels and one with 10 levels. The levels describe a common course of recovery. Not everyone moves smoothly through each level. There are helpful things you can do at each level.

On the following pages, the Rancho Los Amigos scale is on the left side. On the right side you will find ways to help your loved one heal. Some refer to this as low stimulation.

Following these guidelines:

- Provides a calmer space for the patient
- Helps patient tolerate and benefit from therapy
- Keeps patient more safe and comfortable

Rancho Levels of Cognitive Functioning

Level I (1) – No Response

Looks like they are sleeping

Will not respond to sounds, sights, touch, or movement

Level II (2) – Generalized Response

Begins to respond to sounds, sights, touch, or movement

Responds slowly, may not respond every time or in the same way to the same thing

Level III (3) – Localized Response

May be awake on and off during the day

Will move more than before

Reactions will be more specific to what is seen, heard, or felt

Reacts slowly, and not always the same way to the same thing

Begins to recognize family and friends

Begins to follow simple directions

Level IV (4) – Confused and Agitated

Becomes more alert and active

Attention span is short, only a few seconds

May overact or have strange behavior:

- Aggression
- Scream out
- Use abusive language

Focuses on basic needs such as eating, pain control, or going to the bathroom

May be restrained to prevent injury

Will be forgetful, wants to go home

Has a hard time following directions

May recognize family and friends at times

With help may be able to do simple actions such as feeding or dressing self

What can family and friends do to help at Levels 1–4?

Room

- Keep the room quiet
- Keep the room dim or dark
- Close the drapes
- No added decor such as flowers, balloons, banners, posters, cards, pictures

Interacting with patient

- Quiet voice
- One person speaking at a time
- Limit touch except needed to give care
- Give simple instructions
- Speak in simple sentences
- No joking or teasing

Visiting

- Choose 1–2 consistent support persons (based on patient's response) — no limits on visiting for this person(s)
- Other visitors
- Family only
- 1–2 people at a time
- Limit visits to 10 minutes each hour
- No more than 3 people in room at a time (2 is better)
- Let nursing staff know before you leave — put the call light on

Electronics

- No TV/Radio/Music/iPod/Videos
- No Computers/Tablets
- No Phone/Cell Phone use (patient and visitors)

No passes to leave the unit.

Therapy is done in the room.

Rancho Levels of Cognitive Functioning

Level V (5) – Confused and Inappropriate

More alert

Attention span is short, only a few minutes

Does not know the date, where they are, or why they are in the hospital

Follows simple commands

Short-term memory very impaired

Some long-term memory begins to return

May make things up to fill in gaps in memory

May need step by step instruction to do every day self-care tasks such as brushing teeth

May get stuck on an idea or plan and need to be redirected during tasks

Becomes overloaded and restless when tired or too many people are around

More cooperative with family

May wander

May not express emotion

At the first sign of agitation or withdrawal, go back to doing what is in the red box on the previous page.

What can family and friends do to help at Level 5?

Room

- No loud, annoying or ongoing noise
- Lighting as tolerated
- Small amount of room décor. No violent or sexual content. No busy or active posters.

Interacting with patient

- One person speaking at a time
- Touching and handling as tolerated
- Give simple instructions
- Speak in simple sentences
- No joking or teasing

Visiting

- Choose 1–2 consistent support persons (based on patient’s response) – no limits on visiting for this person(s)
- Other visitors
- Family, close friends, clergy
- No more than 2 people at one time
- Limit visits to 30 minutes each hour
- No more than 3 people in room at a time
- Let nursing staff know before you leave, put the call light on

Electronics: Do not use electronics after 8 p.m.

- TV/Radio/Music/iPod/Videos
- Acute unit:
 - 30–60 minutes at a time
 - Off 2 hours before starting again
- Rehab unit:
 - Therapy days: 1 hour after supper
 - Non-therapy days: 30–60 minutes at a time, off 2 hours before starting again
- No use of Computers/Tablets
- No use of Phone/Cell Phone (patient or visitors)

No passes to leave the unit.

Therapy is done in the room or in department at the discretion of the team.

Rancho Levels of Cognitive Functioning

Level VI (6) – Confused and Inappropriate

Attention span is about 30 minutes

Trouble concentrating when it is noisy or too much activity around them

Follows simple directions

Able to complete self-care activities such as eating, dressing, and bathing with help

May be confused by changes in routine

Easily frustrated

Should remember who they are, where they are, and the date

Knows why they are in the hospital but will not understand all the problems they are having

May be more aware of physical problems than problems with thinking

May show impulsive behavior, doing things without thinking

May have unrealistic goals

What can family and friends do to help at Level 6?

No restrictions on:

- Lighting
- Touch or handling
- Noise
- Room décor
- No TV/Radio/Music/iPod/Videos

Computers/tablet use

- Up to 30 minutes 2 times a day with supervision of care team

Phone/cell phone use

- At the discretion of the care team

Interacting with patient

- One person speaking at a time
- Use normal tone of voice
- Give simple instructions
- Speak in simple sentences
- No joking or teasing

Visiting

- Acute care
 - No limits but must follow hospital guidelines
- Rehab unit
 - Support person(s) can visit anytime
 - Other visitors can visit after 4 p.m. on therapy days
 - Non-therapy days visitors may come anytime

Give hints to help the patient know:

- What causes them to be overstimulated
- What happens when they get overstimulated
- How to reduce stimulation around them

Leaving the unit

- Leaving the unit will be at the discretion of the team

Therapy

- Acute unit: Done in the room or therapy department at the discretion of the care team
- Rehab Unit: In therapy department

Rancho Levels of Cognitive Functioning

Level VII (7) – Automatic and Appropriate

Behavior is right for what is happening

May be able to follow a set schedule

Remembers time and place

Able to do self-care without help

Little or no confusion

May still have problems with judgment, safety, and planning

Able to learn new things, but more slowly than before the injury

Has trouble thinking in distracting, busy or stressful situations

May have a hard time with change; may appear rigid and stubborn

Level VIII (8) – Purposeful and Appropriate

May still have memory problems but they are less noticeable

Knows they have thinking and memory problems

Still learns slower than before the injury

Can be independent at home

Can do activities and self-care on their own

May be able to relearn higher level tasks such as driving and job training

Physical, language, or thinking problems may still be noticeable to those who knew the person before the injury

What can family and friends do to help at Levels 7 & 8?

- Encourage person to do self-care and simple activities on their own.
- Prompt the person needed. Offer support when the person needs to make decisions.
- Use normal language. There is no need to simplify what you say.
- Be careful when using slang, joking, or teasing. The person may not understand.
- Encourage the person to continue with therapy.
- Check with the doctor about restrictions for activities such as driving or working.
- Discourage the use of alcohol and non-prescription drugs.
- Talk about their feelings and ways you can give support.
- Seek other counseling and services when needed.

Rancho Levels of Cognitive Functioning

Level IX (9) – Purposeful and Appropriate

Can do more than one thing at a time but may still ask for help at times

Able to use memory aids such as “to do” lists

Able to do familiar tasks on their own

Aware of problems and can fix simple problems

Responds to others needs and feelings

May be easily irritated or frustrated

Can be back at work but may need an easier job

Level X (10) – Purposeful, Appropriate Modified Independent

Can do more than one thing at a time but may need breaks to continue to concentrate

May be able to make and keep their own memory aids

Able to think ahead to avoid problems

Aware of the needs and feelings of others and able to respond correctly

May be depressed at times

May be irritable and become frustrated easily when sick, tired, or under stress

What can family and friends do to help at Levels 9 & 10?

- Give emotional support and encouragement.
- Allow the person freedom to make choices.
- Offer to help when needed.

Adapted from:

- *Family Guide to the Levels of Cognitive Functioning. Rancho Los Amigos Medical Center, Communication Disorders Department.*
- *Patient and Family Guide to Traumatic Brain Injury, Duke Medicine Department of Speech Pathology and Audiology.*
- *A Symposium on TBI Rehabilitation in a Managed Care Environment: An Interdisciplinary Approach to Rehabilitation by Dr. Chris Hagen.*

Medical Complications

Many medical issues may arise while the patient is in the hospital. Below are some of the most common medical complications. Please check with your health care team for more information.

Seizures

Seizures happen because of abnormal electrical activity in the brain. If a seizure occurs, you may see:

- Jerking, stiffening, or shaking movements of the head, body, arms, legs, or eyes
- Staring or not responding
- Chewing, lip smacking, or fumbling movements
- Odd smells, sounds, feelings, tastes, or visual sights
- Sudden tiredness or dizziness
- Inability to speak or understand others
- Loss of bladder or bowel function

Seizures can vary from mild to severe. They can occur in the first days or weeks after a brain injury. Some can occur months or years later.

Most seizures are treated with medicine. Some require proper blood levels to be effective. If someone has a seizure:

- Call for help
- Loosen clothing
- Help the person to a flat surface if possible
- Prevent injury – move furniture and other objects out of the way, etc.
- Do not put anything in the mouth
- Observe what happens and the length of the seizure
- Turn the person on their side when the seizure is over

If a seizure occurs:

- **Do not** drive until you have been advised to do so
- **Do not** climb on ladders or other tall objects
- **Do not** swim alone or be in water

Deep Vein Thrombosis (Blood clot)

Deep Vein Thrombosis (DVT) occurs when a blood clot forms in a deep vein. Blood clots can damage veins. Part of a blood clot called a thrombus can break off and move to the lungs. This is called a pulmonary embolus (PE). A PE is a medical emergency and could cause death.

Common symptoms

A blood clot does not always cause obvious symptoms. If you do have symptoms, they usually happen suddenly.

- Pain, especially deep in the muscle
- Swelling
- Aching or tenderness
- Red or warm skin
- Fever

A blood clot is less likely to occur with:

- Regular activity
- Taking medicine to prevent clots from forming
- Using devices to apply varying pressure to the lower legs

Pressure ulcers

Pressure sores (pressure ulcers or bed sores) happen when pressure on the skin cuts off the blood supply. It usually occurs in areas where bones are close to the surface. The skin and the tissue below break down. Pressure sores may happen if the person stays in one position for too long. These sores can be painful and heal slowly. Pressure sores are less likely with:

- Changing position often
- Supporting the body by using cushions or pillows
- Avoiding rubbing and sliding
- Keeping skin clean and dry
- Eating a healthy diet and getting enough movement
- Checking skin twice a day for signs of breakdown

Fever and Infection

Infections can occur after a brain injury. Often, a fever is the first sign of an infection. When a patient has a fever, tests may be done to find a source. The antibiotics can be used to treat the infection. Common infections include pneumonia and urinary tract.

A fever can also be from the brain injury itself. This happens when the part of the brain that controls body temperature is damaged.

Hydrocephalus

This happens when there is a buildup of fluid in the hollow spaces of the brain known as ventricles. The extra fluid can put pressure on the rest of the brain. A CT scan is usually done if they think it might be hydrocephalus. If the CT scan shows hydrocephalus, the doctor will talk with the neurosurgeon about treatment.

Heterotopic Ossification

Extra bone can form in the body as a result of surgery or trauma. It occurs in the large joints such as the hip or the shoulder. This can cause joints to become:

- Painful
- Swollen
- Inflamed
- Tight

X-rays or a bone scan may be done to see if there is extra bone growth. Treatment may include exercise or surgery.

Fractures and Nerve Injuries

Many brain injuries are caused by trauma, such as car accidents or falls. People with brain injuries may have other injuries as well. One out of 3 people with a brain injury also has a broken bone called a fracture. The same number have injuries to the nerves of their arms and legs. Some of these injuries may not be found until days or weeks later. When the patient is more awake and alert they may begin to show signs of pain or have problems moving. Tests may need to be done to find the problem.

High Blood Pressure (Hypertension)

This can be caused by damage to the part of the brain that controls blood pressure. The doctor may need to do tests to rule out other causes. Anti-hypertensive medication may be used to control the blood pressure.

Medications

Many medicines may be given after a brain injury. Some of these are listed below.

- **Analgesics** are pain medicines used to keep the person comfortable.
- **Antianxiety agents** lessen feelings of uncertainty, nervousness, and fear.
- **Antibiotics** treat or prevent bacterial infections.
- **Anticoagulants** prevent blood clots.
- **Anticonvulsants** prevent and treat seizures (convulsions).
- **Antidepressants** improve or balance a person's mood.
- **Antipsychotics** may be used if the person becomes combative or hostile, has hallucinations, or has problems sleeping.
- **Blood pressure medicines** keep blood pressure from going too high (hypertension) or too low (hypotension).
- **Diuretics** decrease the amount of water in the body and may be used to reduce pressure in the brain.
- **Gastrointestinal (GI) medicines** may:
 - Prevent and treat ulcers
 - Maintain good bowel function
 - Aid in stomach emptying
 - Decrease stomach contents from moving back up into the esophagus (gastric reflux)
- **Muscle relaxants** reduce or treat muscle spasms or spasticity.
- **Sedatives** help the person relax or sleep.
- **Stimulants** help the person be more alert and focused on tasks.

Coping With New Challenges

Cognition – This is how one takes in and uses information.

Attention and Concentration

With a head injury, it may hard to focus.

What you can see	What you can do
<ul style="list-style-type: none">• Restless and easily distracted• Hard to do one or more things at a time• Cannot talk or sit still for long periods of time• Not able to switch from one task or person to another	<ul style="list-style-type: none">• Remove distractions and noises• Do one task at a time• Work in a quiet room• Give information in small amounts

Processing

People with head injuries may have trouble taking in information and reacting to it.

What you can see	What you can do
<ul style="list-style-type: none">• Takes longer to grasp things• Taking longer to understand information• Slower to react and carry out tasks such as getting dressed	<ul style="list-style-type: none">• Focus on task• Allow extra time• Re-read information• Decrease distractions• Ask people to repeat themselves

Memory

Recent memory is most affected.

What you can see	What you can do
<ul style="list-style-type: none">• Trouble learning and keeping new information• Problems recalling daily activities• Repeating the same thing often• Forgetting things very quickly	<ul style="list-style-type: none">• Help to be organized• Use memory aids• Review new information often• Get plenty of sleep

Lack of initiation (self-starting)

What you can see	What you can do
<ul style="list-style-type: none">• Has trouble getting started• Appears to have lack of interest• No “get up and go”	<ul style="list-style-type: none">• Stick to a routine• Break tasks into easy steps• Create a checklist of daily goals• Help to show progress

Planning and organizing

What you can see	What you can do
<ul style="list-style-type: none">• Hard time making daily plans• Problems doing things in the correct order (sequencing)	<ul style="list-style-type: none">• Use memory aids; post easy reminders• Follow a routine• Keep items in the same place• Break tasks into easy steps• Do most important tasks when less tired

Reasoning and judgment

What you can see	What you can do
<ul style="list-style-type: none">• Not able to see a problem or how to solve it• Takes things literally (believes exact words)• Decides on impulse	<ul style="list-style-type: none">• Try not to decide things when tired or stressed• Do not use slang words or ideas• Help identify and solve the problem

Orientation

What you can see	What you can do
<ul style="list-style-type: none">• Not knowing people, places, time or what is going on	<ul style="list-style-type: none">• Use memory aids• Repeat steps and things to know

Task Flexibility (able to shift focus)

What you can see	What you can do
<ul style="list-style-type: none">• Becomes anxious or upset when doing more than one task at a time• Starts another task before completing the first	<ul style="list-style-type: none">• Lessen distractions• Use memory aids

Confabulation (telling stories)

What you can see	What you can do
<ul style="list-style-type: none">• Makes up stories to fill memory gaps• Facts given may be not true• May believe their own stories	<ul style="list-style-type: none">• Do not accuse of lying• Help the person to tell true information

Language

Dysarthria (does not speak clearly)

What you can see	What you can do
<ul style="list-style-type: none">• Slurred speech• Speaking too loud or too soft• Speaking too fast• Change in voice such as hoarseness	<ul style="list-style-type: none">• Ask the person to repeat• Allow time to express self• Use plan by speech therapy

Word finding problems

What you can see	What you can do
<ul style="list-style-type: none">• Problems finding the right word• May say the wrong word	<ul style="list-style-type: none">• Give time to speak• Ask to write words if able• Offer help when needed to find a word

Hard to understand what is said

What you can see	What you can do
<ul style="list-style-type: none">• May understand things wrong	<ul style="list-style-type: none">• Highlight the most important point• Repeat what was said• Rephrase if needed

Does not take turns when talking

What you can see	What you can do
<ul style="list-style-type: none">• Does not stop talking• Does not allow others to speak• Interrupts• Repeats• Does not stay on-topic	<ul style="list-style-type: none">• Redirect• Ask to be brief• Use a hand signal to tell it is another person's turn to speak• Give positive feedback for listening• Make it clear when topics change

Writing problems

What you can see	What you can do
<ul style="list-style-type: none">• Not able to start writing• Writing the same thing over and over• Problems finding words	<ul style="list-style-type: none">• Practice writing:<ul style="list-style-type: none">– Letters– Words– Sentences

Aphasia

(Expressive aphasia) Not able to express thoughts

(Receptive aphasia) Not able to understand

What you can see	What you can do
<ul style="list-style-type: none">• Trouble understanding the spoken word• May not use complete sentences• May not be able to read or write• Trouble attaching meaning to numbers	<ul style="list-style-type: none">• Give positive support for trying to speak• Give time to understand and respond• Speak slowly and clearly• Ask yes or no questions• Use common words but do not “talk down”• Speak in simple sentences• Stick to one idea• Try not to speak for the person• Do not pretend to understand if you do not

Physical Problems

Balance and Falls

It is common to have problems with balance after a head injury.

This can lead to falls. Balance can improve with time and therapy.

What you can see	What you can do
<ul style="list-style-type: none">• Not steady walking or sitting• Holding onto furniture, walls and other objects when walking• Falls	<ul style="list-style-type: none">• Encourage proper use of walking aids such as walkers or canes• Learn how to assist with balance needs• May need supervision once home• Remove throw rugs

Spasticity (spas-TIS-it-ee)

Tightening in muscle tone happens due to disrupted signals from the brain. This can happen while moving or at rest.

What you can see	What you can do
<ul style="list-style-type: none">• Muscle stiffness• Decreased range of motion	<ul style="list-style-type: none">• Follow stretching exercises advised• Use splints as ordered• Watch skin for redness• Medicines may be needed

Loss of movement (Hemiparesis or Hemiplegia)

What you can see	What you can do
<ul style="list-style-type: none">• Absence of movement (hemiplegia) or extreme weakness (hemiparesis)• Decreased feeling in affected areas	<ul style="list-style-type: none">• Assist with exercise• Watch skin for redness or breakdown• Allow extra time• Use adaptive devices as advised• Assist with different positions• Follow advice of therapy

Swallowing problems

Problems with swallowing (dysphagia) happen when food or liquids do not move down the throat as they should. This can happen after brain injury. Sometimes the throat muscles are weak.

Aspiration is when food or liquid goes “down the wrong pipe” and enters the airway or lungs. Some people with swallowing problems do not cough when this happens. This is called silent aspiration.

What you can see	What you can do
<ul style="list-style-type: none">• Choking or coughing while eating• Pocketing of food inside the mouth• Drooling• Poor interest in food due to special diet	<ul style="list-style-type: none">• Learn a safe plan for eating• Help with exercises• Remind to use safe swallow methods

Headache

Headaches are common after a brain injury. Headaches can occur a long time after the injury. There may be different types of headaches depending on the injury and history. Post brain injury headaches usually improve over time.

Treatment Options	What you can do
<ul style="list-style-type: none">• May need to try different medicines• Take all medicines as directed• Do not change medicine without talking to your doctor	<ul style="list-style-type: none">• Rest in a dark, quiet place• Use dark sunglasses in sunlight• Get enough sleep• Exercise daily• Try heat or ice as recommended• Avoid trigger foods like red wine, foods with Monosodium Glutamate (MSG), or certain types of cheese• Do not use caffeine• May need to be watched at first when taking medicines

Fatigue

Fatigue is common after brain injury. Peripheral fatigue is muscle fatigue. Central (mental) fatigue affects ability to think. Learning and working to stay focused is tiring.

What you may see	What you can do
<ul style="list-style-type: none">• Lots of comments about being tired• Needs sleep even after short activities• Poor stamina• Extreme fatigue after a busy time• Slurred speech• Worsened pain, thinking, or mood• Slower thinking speed• Irritability	<ul style="list-style-type: none">• Plan rest breaks• Decrease social activity• Help to set a good pace• Help to save energy for “must do” activities• Set regular exercise• Allow daytime rest for 30 to 60 minutes• Plan appointments when most rested• Learn the person’s signs of fatigue

Sleep

Sleep patterns are worse at first and may get better over time.

What you may see	What you can do
<ul style="list-style-type: none">• Hard to fall asleep or stay asleep• Awake at night, sleeping in the day• Frequent naps• Sleeping too much or too little	<ul style="list-style-type: none">• Limit number and length of day time naps• Avoid caffeine after the morning• Exercise during the day; avoid too close to bedtime• Do not eat or drink too close to bedtime• Avoid screen time close to bedtime• Set a bedtime sleep and waking routine• Keep bed for sleep and sex only, not things like TV or computer• Darken bedroom, use room darkening shades, turn clocks away from sight. Keep room cool• Talk to doctor if worry or nightmares prevent good sleep• Use sleep aids only on a short term basis

Perception and Sensory

Perception is how a person tells what is going on around them. Sensory ability is how a person feels, sees, hears, or smells. These feelings help people respond.

Neglect of one side (Unaware of affected side of body)

What you may see	What you can do
<ul style="list-style-type: none">• Bumps into things• Turns head to the not affected side• Does not see food on the affected side• Does not dress the affected side	<ul style="list-style-type: none">• Stand on the affected side. Ask the person to look toward their affected side• Put the bed and chair so the person has to look toward the affected side

Visual Problems and Visual Field Cut (Lack of part of seeing)

What you may see	What you can do
<ul style="list-style-type: none">• Bumps into things• Blurred or double vision• Sensitive to light• Problems with focus• Trouble with eye movements• Loses place on a page• May see only part of a word or a sentence• Does not eat food on the affected side	<ul style="list-style-type: none">• Remind the person to look around them• Draw a line down the side of the page to show where to stop• May see an eye doctor who is expert in brain injury

Apraxia (Problems doing tasks in movement or speech)

What you may see	What you can do
<ul style="list-style-type: none">• Not using objects or clothes correctly• May use toothbrush to comb hair or a fork to eat soup	<ul style="list-style-type: none">• Show how to use the object or do the movement• Use your hand to guide the person• Use the same routine

Spatial Awareness (Knowing where things are around them)

What you may see	What you can do
<ul style="list-style-type: none">• Not being able to tell the distance of a chair or other object• Missing cup when pouring• Mistakes distance of steps• Reach too far or not enough	<ul style="list-style-type: none">• Keep items in the same place• Contrast colors on the edges of stairs and other objects• Use handrails• Use finger crawling or slide foot when feeling for items

Taste and Smell

What you may see	What you can do
<ul style="list-style-type: none">• Food tastes different• Needs more spices• May eat foods they would not have before• Not able to smell food or other hazards	<ul style="list-style-type: none">• Offer more choices• Work with dietitian• Make sure to have a working smoke alarm

Bowel and Bladder

What you may see	What you can do
<ul style="list-style-type: none">• May not know or able to tell of the need to empty the bowel or bladder• May leak urine or stool• May not be able to pass urine• May have a strong urge or need to go often• Skin problems can result	<ul style="list-style-type: none">• Eat at regular times• Eat high fiber• Drink plenty of liquids• Stay active• Use a toileting plan every 2–3 hours• May need medicines• May need pull-ups• Follow bowel or bladder program if advised

Emotional and Behavioral Changes

A brain injury can change the way someone acts and feels.

Depression

What you may see	What you can do
<ul style="list-style-type: none">• Feeling very sad or anxious most of the time• Less interest in things that were enjoyed before• Feeling very tired• Sleep too much or too little• Problems with thinking, memory, and making decisions• Changes in appetite• Lacks get up and go• Talks about harming themselves	<ul style="list-style-type: none">• Talk about what is positive in their life• Offer activity or exercise• Listen to person's concerns• Offer support• Seek professional help if needed• Call 911 if the person talks about harming themselves

Changing emotion (Emotionally labile)

What you may see	What you can do
<ul style="list-style-type: none">• Laughing or crying too much• Responses that do not fit what has happened. This could be:<ul style="list-style-type: none">– Laughing at something sad– Crying when others are laughing• Emotions change often and quickly	<ul style="list-style-type: none">• Do not compare behavior to before• Medicines might be needed• Stay calm• Try not to become angry or impatient yourself• Reassure• Let the person talk about feelings, provide understanding• Offer activity or exercise

Change in sexual behaviors

What you may see	What you can do
<ul style="list-style-type: none">• More or less interest in sex• Showing too much affection• Making comments that are not proper	<ul style="list-style-type: none">• Help to explain what is not proper• Talk about what is ok to say and do• Let them know sexual feelings are normal• Help to understand sex is private• Agree on what will happen if behavior is not proper in public

Frustration or anger

What you may see	What you can do
<ul style="list-style-type: none">• Little patience• Hard time dealing with change• Lashing out with words or actions• Gets more angry when:<ul style="list-style-type: none">– Tired– New things happen– Stressed	<ul style="list-style-type: none">• Avoid stress• Help grow anger coping skills such as taking breaks in a quiet place• Talk about what is not proper in public• Help make a plan for when angry• Remain calm, walk away if needed• Remind person that feeling this way is part of being brain injured• Do not argue during a stressful time• Talk about what caused outburst later• May need medicines• May need professional help

Change in social skills

What you may see	What you can do
<ul style="list-style-type: none">• Focused only on self• Does not respond to social cues• Not aware of boundaries and others need for personal space• Poor sense of others feelings• Use of dirty words or actions	<ul style="list-style-type: none">• React calmly• Help find other things to talk about• Show how to act correctly• Plan a signal to let the person know when they are doing something not proper

Poor self-control

What you may see	What you can do
<ul style="list-style-type: none">• Saying without thinking “no filter”• Acting without thinking such as walking into traffic• Saying things about people that are not proper	<ul style="list-style-type: none">• Offer another idea or different words to use• Plan a signal to let the person know when they are doing something not proper• Talk about results of poor choices in private

Perseveration (Repeating)

What you may see	What you can do
<ul style="list-style-type: none">• Talks on and on about the same thing	<ul style="list-style-type: none">• Offer another subject to talk about• Give feedback

Impaired self-awareness or self-esteem

What you may see	What you can do
<ul style="list-style-type: none">• Lack of awareness of limits• Trying to do things above their ability• Poor confidence to try things they could do• Seeing themselves in way that is not real• Poor self-worth	<ul style="list-style-type: none">• Share what you see• Use feedback to support• Allow the person to express their feelings• Notice the positives and celebrate them• Choose activities that are within the person’s ability

Problems forming relationships

What you may see	What you can do
<ul style="list-style-type: none">• Does not see or share feeling for others• Focuses only on self	<ul style="list-style-type: none">• Help to show respect• Assist with seeing the needs of others• Show kindness

Safety

Once a person has a brain injury he/she is 3 times more likely to have a second brain injury. After the second brain injury, the odds of having a third brain injury increases by 8 times.

There may be problems with judgment, snap decisions, and motor control. It is important not to drive until deemed safe. Choosing safe activities are a priority to prevent re-injury. It is also necessary to make sure the environment is safe. Most accidents occur in the bathroom and kitchen, places where people spend most of their time.

Personal safety

- Limit number of visitors and length of visits.
- Avoid events that are noisy and crowded.
- Avoid alcoholic drinks.
- Ask your doctor before taking new medications.
- Get enough sleep and take rest breaks.
- Keep light source (including flashlight) within easy reach.

Risk for poor choices in sexual expression or lack of control may be a concern. These problems can impact the patient or others. This may cause emotional harm, sexually transmitted diseases, or unplanned pregnancy. A person with a brain injury could be more vulnerable. Impaired judgment, anger, and impulsive choices can lead to legal problems.

Health care providers are legally required to report information to state and federal agencies. This may include, but is not limited to:

- Harm resulting from a crime
- Suspected abuse and neglect
- Public health concerns

Abuse is causing physical or emotional harm or not giving care required to a dependent person. Neglect is withholding or denying basic care. Self-neglect is when a person does not care for themselves. **Contact local law enforcement or social services if you suspect abuse or neglect.**

Home Safety

To make your living area safe:

- Keep clutter off floors and stairs to prevent falls.
- Remove throw rugs that could cause falls.
- Remove breakable or dangerous objects such as matches, knives, and guns.
- Keep medication in a locked cabinet or drawer.
- Give over-the-counter medicine only with doctor's approval.
- Limit access to dangerous areas such as the bathroom or basement if the person wanders. Wear an identification bracelet if he or she wanders outside.
- Make sure rooms are well lit. Use night lights.
- Have someone stay if the person is very confused or agitated.
- Keep exit doors locked. Consider using an alarm system.
- A mat alarm may be helpful if the person is getting up at night.
- Make sure stairways have sturdy handrails.
- Do not wax or polish floors as they may become slippery.
- Keep keys to any motorized vehicles and machinery secured.
- Do not sleep with a heating pad or electric blanket.

Fire safety

- Check for fire hazards
- Prevent access to radiators or portable heaters
- Install fire extinguishers and smoke detectors
- Plan and practice fire drills

Kitchen safety

- Have good light near stove and sink areas
- Keep oven mitts nearby when cooking
- Make sure any spills are cleaned up to prevent falls
- Keep a well-stocked first aid kit
- Supervise person when:
 - Using appliances
 - Using sharp objects
- Store frequently used items in easy reach

Bathroom safety

- Place toilet paper and supplies within reach
- Keep cleaners in a safe place
- Use nonskid mats in bath tub or shower
- Install grab bars or shower chairs
- Use night lights
- Remove locks on doors

Outdoor safety

- Keep lawn and garden tools safely stored.
- Keep poisons locked up.
- Supervise near pools or other water.
- Be careful when surfaces are uneven.
- Alert neighbors of safety concerns.
- Keep walkways clear of snow, ice, loose gravel, toys, and lawn equipment.
- Consider fence to prevent wandering or getting lost.

Planning for safety

- Make a list of things to remember.
- Keep phone nearby.
- List emergency numbers near the phone.
- Program emergency numbers in phone.
- Consider a personal alert system.

Before starting these high risk activities ask your care team:

- Driving
- Contact sports
- Horseback riding
- Swimming
- Hunting or access to guns
- Use of power tools or sharp objects
- Riding recreational vehicles
- Use of alcohol or other substances such as over-the-counter medicines

Disaster Planning

Emergencies caused by severe weather or disasters can happen with or without warning. Problems with movement, reaction time, hearing, or vision can make responding to disasters even harder. It is good to plan ahead. This includes knowing who you can rely on for support.

Let local emergency services or law enforcement know if you have a disability or someone disabled living at home. A guide is available from the American Red Cross and The Federal Emergency Management Agency. See suggested websites and reading at the end of this book.

Family, Friends, and Patient

Learning to live with a brain injury can be hard. It may take a long time for all of you to adjust. The rehab team will give you information about counseling, resources, and support organizations.

Health and Wellness

General Nutrition

Good nutrition is important for healing and recovery. At first, more calories and protein will be needed. Shakes may be offered to provide more calories and protein. As recovery continues, a well-balanced diet with fruits, vegetables, protein, dairy, and whole grains will provide the best health.

Swallowing may need to be checked to make sure it is safe to eat. If the person is not able to eat or swallow, a feeding tube may be used. Liquid food is given through a tube directly into the stomach or small intestine.

Eating too much or drinking a lot of liquids can happen. The person may forget that they have eaten. They may forget to eat. Set and stick to a schedule for meals and snacks.

Exercise

An ongoing exercise program will help promote strength, balance, and well-being. Being flexible will make it easier to move and be safe. Try to plan 30 minutes of exercise at least 3 times per week. The rehab team can suggest exercises that are best.

Tobacco Cessation (stopping)

Tobacco use (cigarettes, e-cigarettes, pipes, cigars, chewing or spit tobacco) is not allowed in and around Sanford buildings and property. Smoking when oxygen therapy is in use is a serious fire hazard and is not allowed.

Smoking may cause problems with memory and recovery. Quitting tobacco is one of the best things to improve health. Quitting helps reduce tobacco's harmful effects. Many users try 4 or 5 times before they succeed. The best chance of success occurs with a stop-smoking group and the support of family and friends. For more information to stop smoking see resources section.

Substance Use

Some traumatic brain injuries occur due to substance abuse. Sometimes people with a brain injury try to ease effects with alcohol or drugs. This is very dangerous because a brain injury may make your brain more susceptible to the effects of alcohol and drugs.

Mixing a brain injury with misuse of alcohol or drugs raises the risk for:

- Slower recovery
- Worsening of brain injury symptoms
- Making bad decisions
- Having another brain injury
- Seizures
- Family and job problems
- Suicide

Knowing the dangers of substance abuse after brain injury is the first step. Many people who have had a substance abuse problem in the past stop using drugs and alcohol after a brain injury because they understand the dangers. Here are important steps to take:

- **Be honest with the health care team.** Let them know if there are problems with alcohol or drugs.
- **Stick with the treatment program.** People in supervised treatment are less likely to have substance abuse problems.
- **Do not spend too much time alone.** Get friends and family involved in recovery.
- **Join a support group.** Ask your care team if you need help finding one.
- **Do not get discouraged.**

Driving

A brain injury can affect skills needed to drive safely. Do not drive until a driving evaluation has been passed. Driving when not safe or licensed may lead to serious injury and financial loss.

Certain medications can affect driving skills. Seizures can impact the decision to drive. The amount of time needed to be seizure-free for driving will vary depending on the person's condition and state laws.

A driving evaluation after brain injury is very important. Some people will resume driving with special restrictions. Examples would be no interstate driving or driving at night.

Warning signs of unsafe driving

- Driving too fast or too slow
- Not observing signs or signals
- Judging distance inaccurately when stopping or turning
- Slow to make decisions
- Becoming easily frustrated or confused
- Having accidents or near misses
- Drifting across lane markings into other lanes
- Getting lost easily, even in familiar areas

What to do if your loved one wants to drive:

- Ask your doctor for a referral to have a driving evaluation
- Lock up keys if needed
- Report driving to law enforcement if dangerous to self or others

Leisure Activities

Returning to hobbies and pleasant past-times are helpful for healing. A balance between making sure the activity is safe and gaining confidence is important. The rehab team can help with these goals. Hope and patience are helpful.

Preparing for Discharge or Transition

Getting ready to leave the rehab unit can be a time of excitement and some fear. Healing is different for everyone after a brain injury. There will be good days and bad days. When measuring progress, it is helpful to compare your loved one with where he was the day of the injury, not where he was prior to the injury.

A safe plan for leaving the hospital is made together with the patient, family, and team. Some people will be able to go home and some will need more care. Therapy may continue on an outpatient basis.

Get help for financial questions from the social worker. Seek advice and be informed about insurance limits and co-pays. Find out when to call the doctor, go to a clinic or walk-in, and when it is necessary to go to the Emergency Department.

Questions to think about and ask before you leave:

- Are there any needs for transportation?
- Is the home accessible and safe?
- Are there services available to help?
- When are follow-up appointments? How often?
- What medications are needed and how should they be taken?
- What further tests are needed?
- What signs or symptoms should be watched for?

Treatment options

The rehab team will help to set up a plan for ongoing recovery. This will include care providers and therapy that is still needed. Planning for long-term health will include seeing your regular doctor.

Making the Most of Visits with Your Doctor

Getting ready before seeing your doctor will help make these visits more useful. Write down questions to ask. Sign up for electronic chart access. Think about any changes or concerns.

What to bring to the doctor visit:

- A caregiver or trusted person
- A current list of medicines
- A list of other doctors or therapists that are being seen
- Questions to ask or things to tell the doctor
- Copies of outside records

Respite Care (Plan for rest)

Family caregivers are at higher risk of emotional and physical problems than other people would be. Think about a plan to allow caregivers to have rest and relief from their responsibilities.

Self-Advocacy (Looking out for your health needs)

Over time, it is hoped that the brain injured person will begin to look out for more of their own health needs. During recovery, the goal is to return to as much independence as possible. With support, this can be part of future planning.

Returning to school or work

Returning to school or work is often one of the hardest phases of recovery. It is common to become very tired, have a hard time with memory, and struggle socially.

Some people are able to return to their old jobs while others may have more limits. Young adults may not have chosen a career before their injury. Vocational (school and work) assessment and experts may be needed. They can work with the employer to make any changes needed. Programs are also available to assist with returning to school.

A plan will be developed that is based on what help is needed. Workload and hours may need to be adjusted. Over time, this plan may change to increase hours and assignments.

Resources

Resources for Bemidji area

Brain Injury Association of Minnesota

(612) 378-2742

(800) 669-6442

www.biausa.org

Resources for Minnesota

Minnesota Brain Injury Alliance

www.braininjurymn.org

Minnesota Brain Injury Alliance is a proud member of Community Health Charities Minnesota. This is an alliance of leading nonprofit health research and service organizations whose mission is to improve lives affected by chronic illness by investing in health research, services, and education.

Resources for Fargo area

Fargo Mind Matters Support Group

www.heartspringscenter.com

Heart Springs Community Healing Center

2010 North Elm Street

Fargo, ND 58102

(701) 261-3142

Email: heartspringsinfo@gmail.com

1st Thursday of every month from 6–7:30 p.m.

Freedom Resource Center for Independent Living – Fargo

www.freedomrc.org

Freedom Resource Center is a disability rights organization. Freedom Resource Center's mission is to work toward equality and inclusion for people with disabilities through programs of empowerment, community education, and systems change.

2701 9th Avenue South, Suite H

Fargo, ND 58103

(701) 478-0459

(800) 450-0459

Email: freedom@freedomrc.org

Sanford Health – Fargo (Social Group and Recreational Program)

Support group and social/recreational services.

Brain Injury Support Groups

Social and Recreational Programs

1720 University Drive

Conference Room 1-C

Fargo, ND 58103

(701) 280-4769

(800) 828-2901

Second Tuesday of the month from 6:30–8:30 p.m.

HERO, Healthcare Equipment Recycling Organization

www.herofargo.org

HERO, Healthcare Equipment Recycling Organization collects and redistributes donated healthcare materials to benefit those in need.

5012 53rd Street South, Suite C

Fargo, ND 58104

(701) 212-1921

(888) 524-2827

Email: info@HEROfargo.org

Vocational Rehabilitation – Fargo Office

www.nd.gov/dhs/dvr

The primary mission of the North Dakota Vocational Rehabilitation Division is to assist North Dakotans with disabilities to improve their employment opportunities and to assist North Dakota businesses in finding solutions to their disability-related issues.

2624 9th Avenue Southwest

Fargo, ND 58103

(701) 298-4459

(888) 342-4900

Community Options – Fargo

www.communityoptionsnd.com

Community Options, Inc. is dedicated to supporting people, through individual choice, to live a lifestyle which gives dignity and respect.

2701 9th Avenue South

Fargo, ND 58103

(701) 364-2682

(877) 865-1682

Resources for North Dakota

Brain Injury Network – North Dakota

www.ndbin.org

Website has multiple links to local or statewide support groups, educational resources, information for brain injury survivors, family members, and caregivers. This website also helps with referrals to pre-employment training and on the job support. To be eligible for services through the Brain Injury Network–North Dakota you must be a legal resident of ND and have experienced a Traumatic Brain Injury.

Sanford Health – Bismarck (Brain Injury and Stroke Support Group)

Brain Injury and Stroke Support Group

300 North 7th Street

Bismarck, ND 58102

3rd Tuesday of the month each quarter

(701) 323-6696

www.sanfordhealth.org/classes-and-events/Courses/stroke-and-brain-injury-support-group

West Region Brain Injury Support Groups

DCIL-Bismarck Brain Injury Support Group

Support group for survivors and family members.

3111 East Broadway Avenue

Bismarck, ND 58501

4th Thursday of the month 4–5 p.m.

(701) 222-3636

www.dakotacil.org

Dickinson Brain Injury Support Group

Survivor facilitated support group for survivors and family members to share their experiences.

Hawk's Point

1266 Signal Butte

Dickinson, ND 58601

2nd Tuesday of the month at 7 p.m. MST

(701) 260-0098

Minot Brain Injury Support Group

Support group for individuals and family members dealing with brain injury.

Independence, Inc.

300 3rd Avenue SW

Minot, ND 58701

3rd Thursday of the month from 4:30–6 p.m.

(701) 317-4172

Resources for South Dakota

Aberdeen, South Dakota

Rehabilitation Center at Avera St. Luke's Hospital, 4th floor.

3rd Tuesday of every month from 7–8:30 p.m.

(605) 395-6655

Brain Injury Support Group of the Black Hills

Open to individuals with brain injury, their families/caregivers, and professionals

The Brain Injury Rehabilitation Center (formerly called Community Transitions)

803 Soo San Drive

Rapid City, SD

2nd Tuesday of the month from 6–7 p.m.

(605) 718-8446

Brookings Area Brain Injury Support Group

Brookings Hospital

1st Thursday of the month from 3–4 p.m.

(605) 697-6678

Sioux Falls Area Brain Injury Support Group

The support group provides an environment where persons with brain injury

and their families can share accomplishments and struggles and find others who

understand. They try to have an educational speaker at least every 2–3 months.

A monthly newsletter is sent out to those on the mailing list. If you would like to

receive this newsletter or want more information, please contact one of the people

listed below.

The Center for Active Generations

2300 West 46th Street

Sioux Falls, SD.

2nd Saturday of every month from 1–2:30 p.m.

Contacts: Karen Brokenleg (605) 339-0137, Deb Lichty (605) 322-5066

Mary Tommeraasen (605) 367-5260, Julie Brown (605) 328-5194

The Brain Injury Rehabilitation Center

Provides community re-entry services in Rapid City including:

- Counseling
- Cognitive therapy
- Speech therapy
- Community living training (including 24 hour care and ADL training)
- Employment training and placement
- Case management

Lifescape

Provides residential services for people with brain injury in Sioux Falls. (Brain Injury must have occurred prior to the age of 21).

Sunrise Villa Avera

Provides rehabilitative care for those who have experienced a traumatic brain injury. For eligibility and contact information, please contact:

Nurse Consultant Program Manager

Department of Social Services

Sunrise Villa Avera

129 E. Clay Street

Irene, SD 57037

(605) 773-5433

South Dakota Department of Social Services

Provides cost-effective and comprehensive services in cooperation with our partners. Individuals and families are strengthened and supported by:

- Fostering independence and personal responsibility
- Protecting people
- Providing opportunities for individuals to achieve their full potential
- Promoting healthy families and safe communities by ensuring quality

Brain Injury Alliance of South Dakota

A 501(c)(3) nonprofit group that works to help people dealing with brain injury.

They try to:

- Connect people with services and support groups throughout South Dakota
- Advocate for improving and expanding brain injury services in the state.

Tobacco Cessation

smokefree.gov/talk-to-an-expert
(800) QUIT NOW / (800) 784-8669

State Quitlines:

- Iowa: www.quitline.iowa.org (800) QUIT NOW / (800) 784-8669
- Minnesota: www.quitplan.com (888) 354-PLAN / (800) 354-7526
- Nebraska: www.quitnow.ne.gov (800) QUIT NOW / (800) 784-8669
- North Dakota: www.ndhealth.gov/ndquits (800) QUIT NOW / (800) 784-8669
- South Dakota: www.sdquitline.com (866) SD-QUITS / (866) 737-8487
- National Cancer Institute Smoking Quitline: (877) 44U-QUIT / (877) 448-7848

Suggested websites and reading

Brain Injury Association of America
<http://www.biausa.org/>

The Brain Injury Guide and Resources
<http://braininjuryeducation.org/>

Brainline
www.brainline.org

National Institute of Neurological Disorders and Stroke
<http://www.ninds.nih.gov/disorders/tbi/tbi.htm>

National Resource Center for Traumatic Brain Injury – List of articles/
documents
<http://www.tbinrc.com/articles>

Preparing for Disaster for People with Disabilities and other Special Needs
http://www.redcross.org/images/MEDIA_CustomProductCatalog/m4240199_A4497.pdf

Reinventing Our Family blog
<http://www.brainline.org/abbymaslin/>
Abby Maslin gained national recognition for TBI advocacy after her husband, TC, was assaulted and suffered a TBI in 2013. This is her blog.

Head Injury (The Facts), by Audrey Daisley, Rachel Tams, Udo Kischka

Living with Brain Injury: A Guide for Families, Second Edition, by Richard C Senelick, MD and Karla Dougherty

Mindstorms: The Complete Guide for Families Living with Traumatic Brain Injury, by John W. Cassidy, 2009.

Dr. Cassidy explains different types of brain injury; explores common myths; demonstrates how TBI may affect memory, behavior, and social interaction; explores the newest options in treatment and rehabilitation; and shows you how to hold on to your own sense of self as you journey through.

Picking Up the Pieces After TBI: A Guide for Family Members, by Angelle Sander, PhD, Baylor College of Medicine

Successfully Surviving a Brain Injury: A Family Guidebook, From the ER to Selecting a Rehabilitation Facility, by Garry Prowe

In an Instant: A Family's Journey of Love and Healing, by Lee & Bob Woodruff, 2008. In January 2006, Bob Woodruff had just been named co-anchor of ABC's World News Tonight, but then, while he was embedded with the military in Iraq, an IED went off near the tank he was riding in. Bob suffered a traumatic brain injury that nearly killed him. This New York Times Bestseller is an extraordinary story of marriage, family, war, and nation.

Helpful terms

Abstraction – the separation of an idea from a specific instance.

Agitation – excessive motor activity which is usually not productive and repeats. It is often accompanied by shouting or loud complaining. Example: not being able to sit still, pacing, and pulling at clothes or other persons.

Agnosia – unable to recognize a sensory stimulus.

Amnesia – lack of memory for periods of time. Different types or examples are:

- Anterograde amnesia – not able to remember events beginning with the time of the injury; severely decreased ability to learn.
- Retrograde amnesia – loss of memory for events before the injury.
- Post-traumatic amnesia (PTA) – the period of anterograde amnesia following a head injury when the person is not able to store new information.

Anomia – unable to find the correct word.

Apraxia – unable to plan and do a learned voluntary movement smoothly; not due to muscle weakness or failure to understand directions.

Cognitive Rehabilitation – treatment aimed at retraining or recovering mental skills disrupted by a brain injury.

Concrete thinking – difficulty in forming ideas, in speculating about what might be, and in grouping similar things together.

Contusion – bruising which causes tissue damage and bleeding.

Discrimination – the ability to pick out small differences among stimuli, whether something you see, hear, feel, etc.

Dysgraphia – unable to write, not due to motor impairment. Also called agraphia.

Dyslexia – problem with reading.

Euphoria – an exaggerated feeling of well-being, mild elation.

Executive functions – planning, prioritizing, sequencing, self-monitoring, self-correcting, inhibiting, initiating, controlling or changing behavior.

Finger agnosia – unable to tell which finger is being stimulated by touch alone.

Higher cognitive functions – usually refers to judgment, abstraction, problem-solving, planning, etc.

Hydrocephalus – extra cerebrospinal fluid in the brain, causing increased intracranial pressure.

Imperception/Inattention/Suppression/Extinction – all refer to a failure to perceive stimulation on one side of the body when both sides are being stimulated at the same time (double simultaneous stimulation). It is not due to a primary sensory deficit such as deafness, blindness, or numbness. It appears to be an attention deficit that is less severe than neglect. It may occur in a person recovering from neglect.

Individual Program Plan – plan of care written by person with brain injury and/or family with the team’s help and has reachable goals prior to discharge.

Memory - recording of new information. There are many types of memory, depending on the person’s orientation. Some of the more common types of memory are:

- Registration – a very brief sensory/memory function, when information enters the memory system. It is then entered into short-term memory or is lost. Very resistant to impairments.
- Short-term memory – working memory with a limited capacity. Its contents are in conscious awareness. Lasts 30 seconds to several minutes.
- Long-term memory – more permanent storage of memory.
- Immediate recall – immediate repetition of information.
- Delayed recall – recall of material after a delay, often with other events or material being introduced to prevent active rehearsal.
- Verbal memory – memory for verbal information. Assumed to reflect functioning of the deep structures of the left temporal lobe.
- Nonverbal memory – memory for numbers, spacial relationships, etc. Assumed to be based in the deep structures of the right temporal lobe.
- Episodic memory – memory for ongoing events in a person’s life. More easily impaired than memory of facts (semantic memory), perhaps because rehearsal or repetition tends to be minimal.
- Semantic memory – memory for facts, usually learned through repetition.

Post-Traumatic Amnesia – a state of acute confusion with cognitive impairment (such as problems with perception, thinking, remembering and concentration). During this time, patients often cannot concentrate long enough to capture anything in their memory.

Self-monitoring – awareness of one’s behavior and how accurate or appropriate that behavior is.

Sitter – a companion who sits with the person as needed to ensure the person is safe and will not harm themselves.

Speech – oral expression of language; talking.

Team Conference (staffing) – a periodic meeting (usually every week) of the rehabilitation team. The person’s progress, rehabilitation goals, and estimated length of stay are discussed and documented at the team conference. They are then discussed with the person with brain injury and their family.

Total Parenteral Nutrition (TPN) – provides all necessary nutrients (calories, protein, vitamins, etc.) in an intravenous (IV) solution.

Tremors – an involuntary trembling movement such as quivering or shaking motions, usually caused from weakness or disease.

Tube feeding – a tube placed into the stomach or small intestine that allows a solution providing all necessary nutrients (such as calories, protein, vitamins, etc.) to be given.

Portions of this booklet adapted from Krames on Demand 2000-2016 The StayWell Company, LLC. 780 Township Line Road, Yardley, PA 19067. All rights reserved. This information is not intended as a substitute for professional medical care. Always follow your healthcare professional’s instructions.

Portions of this booklet adapted from Model Systems Knowledge Translation Center. American Institutes for Research 1000 Thomas Jefferson Street, NW, Washington, DC 20007. Available at: www.MSKTC.org/TBI

Blank lined writing area with a thick dark blue horizontal bar at the top and a gradient blue horizontal bar at the bottom.

Blank lined page with a dark blue header and footer bar.

