



# Understanding Brain Injury

**SANFORD**<sup>®</sup>  
HEALTH

# Welcome

This book has been written for patients who have had a brain injury and their families. It will help you understand the nature and treatment of a brain injury. We want to help you learn and be involved in the plan of care. When you have questions, please ask.

## The Brain Injury 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:

- Choose one person to be the mail contact for family and friends
- 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

### Health Care Professionals

- Doctors
- Advanced Practice Providers
- Nurses
- Pharmacists
- Dietitians
- Case Management
- Spiritual Care
- Respiratory Therapists
- Occupational Therapists
- Physical Therapists
- Speech Therapists
- Therapeutic Recreation Specialists

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## Notes

This space can be used to:

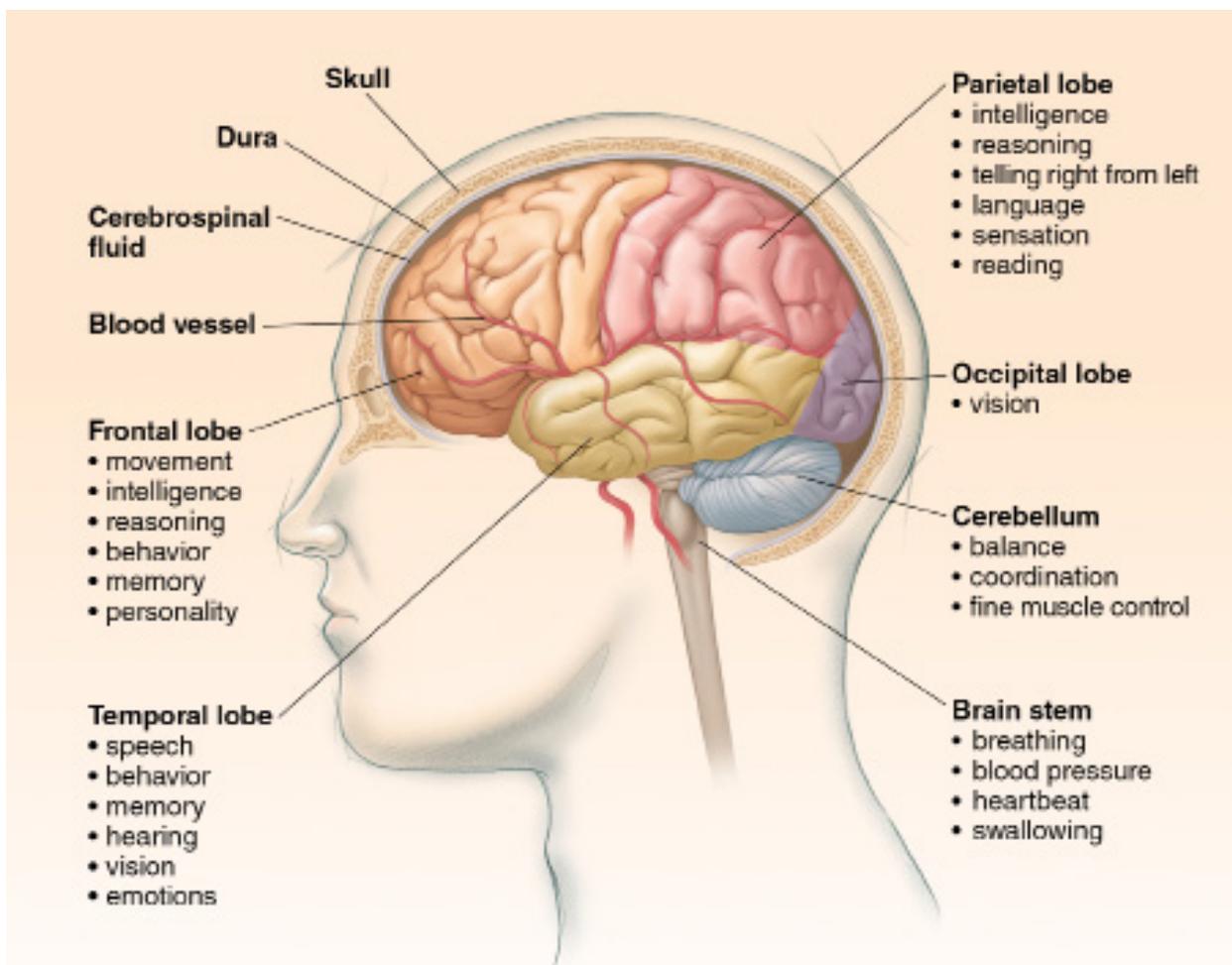
- Draw pictures of the injury
- Write down what the doctor is telling you
- Write down your questions

# About Brain Injury

## How the Brain Works

Different parts of the brain have different functions:

- **Front of your brain** is the center for emotions and reasoning. This is where most of your personality comes from. Your long-term memory is stored here.
- **Sides of your brain** (temporal lobes) store your short-term memory.
  - **Right side of your brain** controls the left side of your body.
  - **Left side of your brain** controls the right side of your body. It also controls most of your speech and language skills. In most people, this is the dominant side.
- **Brain stem** controls basic body functions such as breathing, blood flow, and swallowing.
- **Back of your brain** controls vision.
- **Cerebellum** controls posture, balance, and coordination.



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# Protecting the Brain

Three layers of tissue, called meninges, help protect the brain:

- The outer layer is the **dura mater**. It 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 is the **pia mater**. It 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

### Non-Traumatic Brain Injuries (Acquired)

Non-traumatic brain injuries have non-violent causes. Some of the more common causes 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. If the aneurysm ruptures, the brain may be damaged.
- **Brain Tumor** – Damage to the brain may be caused by the tumor or by surgery, chemotherapy, or radiation used to treat the tumor.
- **Hypoxia** – Not enough oxygen getting 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 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

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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.

## Traumatic Brain Injuries

Traumatic brain injuries have violent causes such as vehicle accidents, sports injuries, and assaults. Types of traumatic injuries:

- **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.
- **Concussion** – A concussion is caused by a direct blow to the head or body. This may not show up on a medical test. The person may or may not lose consciousness.
- **Bleeding (hemorrhage) inside the skull**
  - 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 (hematoma) can form.
    - 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 dural lining outside the brain
    - Intracerebral – Bleeding into the brain tissue
    - Subarachnoid – Bleeding around the arachnoid lining of the brain
- **Contusion** - Bruising of the brain that may cause it to swell
- **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). This can be a very dangerous and life threatening condition.

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# Tests and Procedures

## Brain Scan

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

- It uses a special x-ray machine that 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 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.

## 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.

- The skin is numbed.
- A thin tube (catheter) is placed 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 and may need to lie flat for a time after the pictures are taken.

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## 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 be still and not talk during the test.

## Lumbar Puncture

This procedure is used to remove a small amount of spinal fluid from the lower back. The fluid 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.
- A needle will be placed between two of the spine bones.
- A small amount of spinal fluid will be removed and sent for testing.
- The patient will need to be still and not talk during the test.

## 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

This evaluation includes an interview and tests. It is used to help decide about returning to school, work, or other activities. It measures:

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

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# Critical Care (Intensive Care Unit)

A stay in 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
- Control brain pressure and swelling
- Keep the brain as quiet as possible to allow it to heal

Doctors and nurses use a neuro assessment to track the patient's ability to respond.

Critical care can be overwhelming. There are machines and noises that may cause you to feel anxious. You will have many questions. Please write them down and ask. Some questions will be hard to answer and may take time.

## Tubes and Equipment

Tubes and equipment are used to monitor a person with a brain injury and assist with care. Some of the tubes and equipment that may be used are:

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 a larger vein 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 that 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 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 uses small patches placed on the chest to check the heart. The screen 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.
Intravenous (IV) line	A thin plastic tube placed into a vein to give medicines, fluids, and blood products. A pump is used to give 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 brain tissue oxygen (PbtO <sub>2</sub> ) 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.
Pupillometer	A camera that takes pictures of the eye to measure how the pupil changes when exposed to light.
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.

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# 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

Following these guidelines:

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



## Rancho Levels of Cognitive Function

### 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, or 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 Function

### 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 Function

### Level V (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

#### Computer/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

#### Interacting with patient

- 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 care team
- Rehab Unit: In therapy department

## Rancho Levels of Cognitive Function

### 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 and 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 Function

### 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

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

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

### 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

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.

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# 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

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## Deep Vein Thrombosis (DVT)

A deep vein thrombosis is a blood clot that 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.

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

- 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 Injuries

Pressure injuries (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 injuries may happen if the person stays in one position for too long. They can be painful and heal slowly. Pressure injuries 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. Common infections include pneumonia and urinary tract infections. Your doctor may treat your infection with antibiotics.

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

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## Hydrocephalus

This happens when there is a buildup of CSF 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.

Symptoms of hydrocephalus may include:

- Headaches more often and/or more severe
- Increased sleepiness, hard to stay awake
- Changes in balance
- Changes in speech

## 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.

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# 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** decrease 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.

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# Coping With New Challenges

## Cognition

This is how a person understands and uses information.

### Attention and Concentration

#### What you can see

- Restless and easily distracted
- Hard to do one or more things at a time
- Cannot talk or sit still for long
- Not able to switch from one task or person to another
- Trouble focusing

#### What you can do

- Remove distractions and noises
- Do one task at a time
- Work in a quiet room
- Give information in small amounts

## Processing

#### What you can see

- Takes longer to grasp things
- Taking longer to understand information
- Slower to react and carry out tasks such as getting dressed

#### What you can do

- Focus on task
- Allow extra time
- Re-read information
- Decrease distractions
- Ask people to repeat themselves

## Memory

#### What you can see

- Recent memory is most often affected
- Trouble learning and keeping new information
- Problems recalling daily activities
- Repeating the same thing often
- Forgetting things very quickly

#### What you can do

- Help to be organized
- Use memory aids
- Review new information often
- Get plenty of sleep
- May need supervision when first taking medicines
- Encourage to take all medications as directed

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## Lack of Self-Initiation

### What you can see

- Has trouble getting started
- Appears to lack interest
- No “get up and go”

### What you can do

- 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

- Hard time making daily plans
- Problems doing things in the correct order (sequencing)

### What you can do

- 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 least tired

## Reasoning and Judgment

### What you can see

- Not able to see a problem or how to solve it
- Takes things literally (believes exact words)
- Decides on impulse

### What you can do

- Help identify and solve the problem
- Do not use slang words or ideas
- Try not to decide things when tired or stressed

## Orientation

### What you can see

- Not knowing people, places, time or what is going on

### What you can do

- Use memory aids
- Repeat steps and things to know

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## Task Flexibility (Able to Shift Focus)

### What you can see

- Becomes anxious or upset when doing more than one task at a time
- Starts another task before completing the first

### What you can do

- Reduce distractions
- Use memory aids

## Confabulation (Telling Stories)

### What you can see

- Makes up stories or gives facts that are not true to fill memory gaps
- May believe their own stories

### What you can do

- Do not accuse of lying
- Help the person to tell true information

## Language

This is how one understands and uses information.

## Dysarthria (Does Not Speak Clearly)

### What you can see

- Slurred speech
- Speaking too loud or too soft
- Speaking too fast
- Change in voice such as hoarseness

### What you can do

- Ask the person to repeat
- Allow time to express self
- Use plan by speech therapy

## Word Finding Problems

### What you can see

- Problems finding the right word
- May say the wrong word

### What you can do

- Give time to speak
- Ask to write words if able
- Offer help when needed to find a word

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## Hard to Understand What is Said

### What you can see

- May not understand correctly

### What you can do

- Highlight the most important point
- Repeat what was said
- Rephrase if needed

## Does Not Take Turns When Talking

### What you can see

- Does not stop talking
- Does not allow others to speak
- Interrupts
- Repeats
- Does not stay on-topic

### What you can do

- 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

- Not able to start writing
- Writing the same thing over and over
- Problems finding words

### What you can do

- Practice writing:
  - Letters
  - Words
  - Sentences

---

## Aphasia

Expressive aphasia is not being able to express thoughts.

Receptive aphasia is not being able to understand.

### What you can see

- Trouble understanding the spoken word
- May not use complete sentences
- May not be able to read or write
- Trouble attaching meaning to numbers

### What you can do

- What you can do
- 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 & Falls

#### What you can see

- Not steady when walking or sitting
- Holding onto furniture, walls and other objects when walking
- Falls

#### What you can do

- 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

#### What you can see

- Muscle stiffness
- Decreased range of motion

#### What you can do

- Follow stretching exercises advised
- Use splints as ordered
- Watch skin for redness
- Medications may be needed

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## Loss of Movement (Hemiparesis or Hemiplegia)

### What you can see

- Absence of movement (hemiplegia) or extreme weakness (hemiparesis)
- Decreased feeling in affected areas

### What you can do

- 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

### What you can see

- Choking or coughing while eating
- Pocketing of food inside the mouth
- Drooling
- Poor interest in food due to special diet

### What you can do

- Learn a safe plan for eating
- Help with exercises
- Remind to use safe swallow methods

## Headache

### What you may see

- Headaches may occur long after the injury
- Usually improve over time
- May need to try different medicines

### What you can do

- 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
- Do not change medications without talking to the doctor

---

## Fatigue (Extreme Tiredness)

Physical or muscular fatigue makes it hard to move or be active.

Mental fatigue affects the ability to think.

### What you may see

- 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

### What you can do

- 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

### What you may see

- Hard to fall asleep or stay asleep
- Awake at night, sleeping in the day
- Napping often
- Sleeping too much or too little
- Sleep patterns are worse at first and may get better over time

### What you can do

- Limit number and length of day time naps
- Avoid caffeine after noon
- 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 for a short time

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## 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 to what is happening in their environment.

### Neglect of One Side (Unaware of Affected Side of Body)

#### What you may see

- Bumps into things
- Turns head to the not affected side
- Does not see food on the affected side
- Does not dress the affected side

#### What you can do

- 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 (Not Seeing Everything)

#### What you may see

- 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 one side of the plate or tray

#### What you can do

- 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 or Talking)

#### What you may see

- Not using objects or clothes correctly
- May use toothbrush to comb hair or a fork to eat soup
- Difficulty making the sounds needed to say words

#### What you can do

- Show how to use the object or do the movement
- Use your hand to guide the person
- Follow the same routine

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## Spatial Awareness (Knowing Where Things Are Around Them)

### What you may see

- 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 far enough

### What you can do

- 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

- Food tastes different
- Needs more spices
- May eat foods they would not have before
- Not able to smell food or other hazards

### What you can do

- Offer more choices
- Work with dietitian
- Make sure to have a working smoke alarm

## Bowel and Bladder

### What you may see

- 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

### What you can do

- Eat at regular times
- Eat foods high in 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

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## Emotional and Behavioral Changes

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

### Depression

#### What you may see

- 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 self or others

#### What you can do

- 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 self or others

### Changing Emotion (Emotionally Labile)

#### What you may see

- What you may see
- Laughing or crying too much
- Responses that do not fit what has happened. This could be:
  - Laughing at something sad
  - Crying when others are laughing
- Emotions change often and quickly

#### What you can do

- Do not compare behavior to before
- Medicines might be needed
- Stay calm
- Try not to become angry or impatient
- Reassure the person
- Let the person talk about feelings, provide understanding
- Offer activity or exercise

---

## Change in Sexual Behaviors

### What you may see

- More or less interest in sex
- Showing too much affection
- Making comments that are not appropriate

### What you can do

- Help to explain appropriate behavior
- 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** appropriate in public

## Frustration or Anger

### What you may see

- Little patience
- Hard time dealing with change
- Lashing out with words or actions
- Gets more angry when:
  - Tired
  - New things happen
  - Stressed

### What you can do

- Avoid stress
- Help grow anger coping skills such as taking breaks in a quiet place
- Talk about what is inappropriate 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

- 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 rude or inappropriate words or actions

### What you can do

- React calmly
- Help find other things to talk about
- Show how to act appropriately
- Plan a signal to let the person know when they are doing something inappropriate

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## Poor Self-Control

### What you may see

- Saying without thinking “no filter”
- Acting without thinking such as walking into traffic
- Saying things about people that are **not** appropriate

### What you can do

- 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

- Talks on and on about the same thing

### What you can do

- Offer another subject to talk about
- Give feedback

## Impaired Self-Awareness or Self-Esteem

### What you may see

- Lack of awareness of limits
- Trying to do things above their ability
- Lack of confidence to try things they could do
- Seeing themselves in a way that is not real
- Lack of self-worth

### What you can do

- 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

- Does not see or share feeling for others
- Focuses only on self

### What you can do

- Help to show respect
- Assist with seeing the needs of others
- Show kindness

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# Safety

Once a person has a brain injury they are 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.**

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## Home Safety

- Remove breakable or dangerous objects such as matches, knives, and guns.
- Limit access to dangerous areas such as the bathroom or basement if the person wanders. Wear an identification bracelet if they wander outside.
- Have someone stay if the person is very confused or agitated.
- Remove locks on bathroom doors.
- Keep exit doors locked. Consider using an alarm system.
- A mat alarm may be helpful if the person is getting up at night.
- Keep keys to any motorized vehicles and machinery secured.
- Do not sleep with a heating pad or electric blanket.
- Have good light near stove and sink areas.
- Keep oven mitts nearby when cooking.
- Clean up spills right away.
- Keep a well-stocked first aid kit.
- Supervise person when:
  - Using appliances
  - Using sharp objects
- Store frequently used items in easy reach.
- Keep cleaners in a safe place.
- Use nonskid mats in bath tub or shower.
- Install grab bars or shower chairs.
- Do not wax or polish floors as they may become slippery.
- Keep clutter off floors and stairs.
- Remove throw rugs.
- Make sure rooms are well lit. Use night lights.
- Have sturdy handrails on stairways.

## Fire Safety

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

## Medication Safety

- Keep medication in a locked cabinet or drawer.
- Give over-the-counter medicine only with doctor's approval.

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## 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.

## Ask Your Care Team Before Starting These High Risk Activities:

- 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 without warning. Problems with movement, reaction time, hearing, or vision can make responding to disasters difficult. 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. You will find 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.

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# 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.

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.

## Stop Using Nicotene Products

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

Nicotine may cause problems with memory and recovery. Stopping the use of nicotine is a good way to improve health and reduce nicotine's harmful effects. Many people try to quit 4 or 5 times before they succeed. The best chance of success occurs with attending a group and the support of family and friends. For more information to stop using nicotine products, look in the resources section of this book.

## 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.

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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.**

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## 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 of restrictions 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
- Not judging distance correctly 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 the 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 is 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.

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# 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 how they were the day of the injury, not how they were before 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 after leaving the hospital.

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, or 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

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## **Respite Care (Plan for Rest)**

Family caregivers are more likely to have emotional and physical problems. 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.

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# Resources

## National

### Brain Injury Association of America

[www.biausa.org](http://www.biausa.org)

(612) 378-2742

Toll Free: (800) 669-6442

## Minnesota

### Minnesota Brain Injury Alliance

[www.braininjurymn.org](http://www.braininjurymn.org)

This is an alliance of leading nonprofit health research and service organizations whose mission is to raise awareness and enhance the quality of life for all people affected by brain injury. They have a Resource Facilitation (RF) program. It is a free, statewide, telephone support service and information line for people living in MN who have had a brain injury or stroke, their loved ones, and the professionals who work with them throughout their healthcare and recovery journey. The RF program staff provides individualized support education and connection to community programs and resources.

## Bemidji

### Survivors of Stroke and TBI Support Group

4th Tuesday of each month from 2:30 – 4:30 p.m.

Sanford Bemidji Medical Center

Education Center A/B

Bemidji, MN 56601

(218) 333-5856

[Bemidji\\_Stroke@sanfordhealth.org](mailto:Bemidji_Stroke@sanfordhealth.org)

## Fergus Falls

### Freedom Resource Center for Independent Living

[www.freedomrc.org](http://www.freedomrc.org)

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

125 W Lincoln #7

Fergus Falls, MN 56537

(218) 998-1799

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## North Dakota

### Brain Injury Network

[www.ndbin.org](http://www.ndbin.org)

The Brain Injury Network 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.

### Vocational Rehabilitation

[www.nd.gov/dhs/dvr](http://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. Regional offices are located throughout North Dakota. Addresses and phone numbers can be found on the website.

(701) 328-8950

Toll-Free: (800) 755-2745

Email: [dhsvr@nd.gov](mailto:dhsvr@nd.gov)

### Community Options

[www.communityoptionsnd.com](http://www.communityoptionsnd.com)

Dedicated to supporting people, through individual choice, to live a lifestyle that gives dignity and respect. Many locations throughout North Dakota. Go to the website or call the main office for more information.

#### **Bismarck** – main office

4909 Shelburne St  
Bismarck, ND 58503 (701) 223-2417  
Toll-Free: (800) 823-2417

#### **Devil's Lake**

425 South College Dr, Suite 3  
Devils Lake, ND 58301  
(701) 662-3110  
Toll-Free: (877) 773-8272

#### **Dickinson**

193 24th St E, Suite 103  
Dickinson, ND 58601  
(701) 483-2417  
Toll-Free: (866) 830-7138

#### **Fargo**

2701 9th Ave S, Suite E  
Fargo, ND 58103  
(701) 364-2682  
Toll-Free: (877) 865-1682

#### **Fort Yates**

100 Standing Rock Ave  
PO Box 362  
Fort Yates, ND 58538  
(701) 854-4379  
Toll-Free: (866) 597-6749

#### **Grand Forks**

2300 Library Circle  
Grand Forks, ND 58201  
(701) 772-1715  
Toll-Free: (888) 772-1715

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**Jamestown**

420 20th St SW  
Jamestown, ND 58401  
(701) 952-0220  
Toll-Free: (877) 952-0220

**Minnewaukan**

816 3rd Ave N  
PO Box 37  
Fort Totten, ND 58335  
(701) 766-4427  
Toll-Free: (866) 349-8621

**Minot**

300 3rd Ave SW, Suite D & E  
Minot, ND 58702  
(701) 852-0174  
Toll-Free: (866) 349-8619

**Williston**

309 Washington Ave, Suite 402  
Williston, ND 58803  
(701) 609-5329

**Freedom Resource Center for Independent Living**

[www.freedomrc.org](http://www.freedomrc.org)

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

**Fargo – main office**

2701 9th Ave S, Suite H  
Fargo, ND 58103  
(701) 478-0459  
Toll-Free: (800) 450-0459  
Email: [freedom@freedomrc.org](mailto:freedom@freedomrc.org)

**Lisbon**

701 Main Ave  
Lisbon, ND 58504  
(701) 683-6850

**Jamestown**

300 2nd Ave NE, Suite 226  
Jamestown, ND 58401  
(701) 252-4693

**Wahpeton**

315 11th St N  
Wahpeton, ND 58075  
(701) 672-1649

**Bismarck****Sanford Health – Brain Injury and Stroke Support Group**

3rd Tuesday of the month each quarter

300 N 7th St  
Bismarck, ND 58102  
(701) 323-6696

[www.sanfordhealth.org/classes-and-events/Courses/stroke-and-brain-injurysupport-group](http://www.sanfordhealth.org/classes-and-events/Courses/stroke-and-brain-injurysupport-group)

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## **West Region Brain Injury Support Group**

Dakota Center for Independent Living (DCIL)

4th Thursday of the month 4 to 5 p.m.

3111 E Broadway Ave

Bismarck, ND 58501

(701) 222-3636

[www.dakotacil.org](http://www.dakotacil.org)

## **Dickinson**

### **Brain Injury Support Group**

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

Hawk's Point

1266 Signal Butte

Dickinson, ND 58601

(701) 260-0098

## **Fargo**

### **Sanford Health - Brain Injury Support Group and Social Group/Recreational Program**

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

1720 University Dr

Conference Room 1-C

Fargo, ND 58103

(701) 280-4769

Toll-Free: (800) 828-2901

### **Mind Matters Support Group**

[www.heartspringscenter.com](http://www.heartspringscenter.com)

Contact for date and time of support group.

Heart Springs Community Healing Center

2010 Elm Street N

Fargo, ND 58102

(701) 261-3142

Email: [heartspringsinfo@gmail.com](mailto:heartspringsinfo@gmail.com)

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## **HERO - Healthcare Equipment Recycling Organization**

[www.herofargo.org](http://www.herofargo.org)

Collects and redistributes donated healthcare materials to benefit those in need.

5012 53rd St S, Ste C

Fargo, ND 58104

(701) 212-1921

Toll-Free: (888) 524-2827

Email: [info@HEROfargo.org](mailto:info@HEROfargo.org)

## **Minot**

### **Brain Injury Support Group**

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

Independence, Inc.

300 3rd Ave SW

Minot, ND 58701

(701) 317-4172

## **South Dakota**

### **Brain Injury Alliance of South Dakota**

[braininjurysd.org](http://braininjurysd.org)

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

Main office:

4304 S Glenview Rd

Sioux Falls, SD 57103

### **Lifescape**

[www.lifescapsd.org](http://www.lifescapsd.org)

Provides residential services for people with brain injury that occurred before the age of 21.

Email: [info@LifeScapeSD.org](mailto:info@LifeScapeSD.org)

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## **South Dakota Department of Social Services**

dss.sd.gov

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

Main office:

700 Govers Dr

Pierre, SD 57501

### **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 St

Irene, SD 57037

(605) 773-5433

## **Aberdeen**

### **Brain Injury Support Group**

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

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

(605) 395-6655

## **Brookings**

### **Brain Injury Support Group**

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

Brookings Hospital

(605) 697-6678

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## Rapid City

### Brain Injury Support Group of the Black Hills

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

The Brain Injury Rehabilitation Center (formerly called Community Transitions)

803 Soo San Drive

Rapid City, SD 57702

(605) 718-8446

### The Brain Injury Rehabilitation Center at Black Hills Works

[blackhillsworks.org/who-we-are/our-affiliates/brain-injury-rehabilitation-center](http://blackhillsworks.org/who-we-are/our-affiliates/brain-injury-rehabilitation-center)

Provides community re-entry services including:

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

#### Physical Address:

Black Hills Works

3650 Range Road

Rapid City, SD 57702-2104

#### Mailing Address:

Black Hills Works

PO Box 2104

Rapid City, SD 57709-2104

## Sioux Falls

### Brain Injury Support Group

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.

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

The Center for Active Generations

2300 W 46th St

Sioux Falls, SD

Contacts:

- Karen Brokenleg (605) 339-0137
- Deb Lichty (605) 322-5066
- Mary Tommeraasen (605) 367-5260
- Julie Brown (605) 328-5194

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## Stop Using Nicotene

[smokefree.gov/talk-to-an-expert](http://smokefree.gov/talk-to-an-expert)

(800) QUIT NOW / (800) 784-8669

State Quitlines:

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

## Suggested Websites

### Brain Injury Association of America

[biausa.org](http://biausa.org)

### The Brain Injury Guide and Resources

[braininjuryeducation.org](http://braininjuryeducation.org)

### Brainline

[brainline.org](http://brainline.org)

### National Institute of Neurological Disorders and Stroke

[ninds.nih.gov/disorders/tbi/tbi.htm](http://ninds.nih.gov/disorders/tbi/tbi.htm)

### National Resource Center for Traumatic Brain Injury – List of articles and publications

[tbinrc.com/articles](http://tbinrc.com/articles)

### Preparing for Disaster for People with Disabilities and other Special Needs

[redcross.org/images/MEDIA\\_CustomProductCatalog/m4240199\\_A4497.pdf](http://redcross.org/images/MEDIA_CustomProductCatalog/m4240199_A4497.pdf)

### *Reinventing Our Family* blog

[brainline.org/abbymaslin](http://brainline.org/abbymaslin)

Abby Maslin gained national recognition for TBI advocacy after her husband, TC, was assaulted and suffered a traumatic brain injury in 2013. This is her blog.

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## Suggested Reading

### *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.

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# Definitions

**Abstraction** – the separation of an idea from a specific case.

**Agitation** – more motor activity than is needed. This activity is usually not productive and repeats. It often goes along with shouting or loud complaining. Example: not being able to sit still, pacing, and pulling at clothes or other people.

**Agnosia** – not being able to recognize objects, faces, sounds or smells because the brain cannot interpret the sensory information.

**Amnesia** – lack of memory for periods of time. This may be:

- Loss of memory for events that happened before the injury
- Not being able to remember things that happen after the injury
- Not being able to learn new things

**Anomia** – not able to find the correct word.

**Apraxia** – not able to plan and do a learned voluntary movement smoothly or initiate speech; **not** due to muscle weakness or failure to understand the directions.

**Aspiration** – when food or liquid goes into the airway or lungs. If this happens and the person does not cough, it is called silent aspiration.

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

**Concrete Thinking** – forming ideas, wondering about what might be and grouping similar things together.

**Contusion** – bruising which causes tissue damage and bleeding, usually from a direct hit to the head.

**Discrimination** – the ability to pick out small differences among things you see, hear, feel, touch, or smell.

**Dysgraphia** – unable to write, not due to muscle weakness or paralysis. Also called agraphia.

**Dyslexia** – problem with reading, spelling, and the ability to match letters to sounds.

**Dysphagia** – problems with swallowing; foods and fluids do not move down the throat as they should.

**Euphoria** – an exaggerated feeling of well-being, happiness, and self-confidence.

**Executive Functions** – the mental skills that allow a person to carry out any task. It usually refers to judgement, abstract thinking, problem solving, planning, organizing, and ability to change or control behavior.

**Fatigue** – extreme tiredness.

**Finger agnosia** – unable to tell which finger is being touched.

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

**Hypothermia** – a life-threatening emergency when body temperature drops below normal levels.

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**Imperception/Inattention/Suppression/Extinction** – all of these are a failure to notice stimulation on one side of the body when both sides are being stimulated at the same time. Not due to a sensory problem such as deafness, blindness, or numbness. An attention problem less severe than unilateral spatial inattention but may occur in someone recovering from this.

**Individual Program Plan** – plan of care with reachable goals written before leaving the hospital.

**Memory** – recording new information in the brain. There are many types of memory including:

- Short-term memory – from when a person first becomes aware of something, lasts for 30 seconds to several minutes.
- Long-term memory – more permanent storage of memories.
- Immediate recall – able to repeat information immediately after learning it.
- Delayed recall – recalling information after a time, often with other things happening preventing original information from being reviewed.
- Verbal memory – ability to remember words, what you read or someone says to you.
- Nonverbal memory – memory for numbers, images, faces, sounds, tastes, and feelings.

**Perseveration** – repeating words or talking on and on about the same thing.

**Post-Concussive Syndrome** – when symptoms last long after a concussion or mild traumatic brain injury causes bruising and tissue damage in the brain.

**Post-Traumatic Amnesia** – acute confusion with cognitive impairment such as problems with perception, thinking, remembering and concentration. Patients often cannot concentrate long enough to get anything into their long-term memory.

**Self-monitoring** – being aware of your own behavior and knowing if that behavior is appropriate.

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

**Spasticity** – tightening in muscle tone due to disrupted signals from the brain. This can happen while moving or at rest.

**Spatial Awareness** – knowing where things are around you.

**Speech** – expressing thoughts in spoken words; talking.

**Team Conference (staffing)** – a meeting of the rehabilitation team that is usually held every week. The person's progress, rehabilitation goals, and estimated length of stay are discussed and documented.

**Total Parenteral Nutrition (TPN)** – provides all needed nutrients (calories, protein, vitamins) in an IV solution.

**Tremors** – an involuntary quivering or shaking usually caused from weakness or disease.

**Tube Feeding** – a solution providing all needed nutrients (calories, protein, vitamins) given through a tube placed into the stomach or small intestines.

**Unilateral Spatial Inattention (neglect)** – not aware of the affected side of the body.





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## Advice for Families and Loved Ones

Family and friends will be able to visit, but visits may be limited. Please talk with the nursing staff before visiting your loved one. Each situation is different. The nurses will give you guidance for visiting.

You will spend a lot of time and energy caring for and thinking about your loved one. Allow yourself to get away. Take a walk. Invite friends or family members to join you.

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](http://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

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

- 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.

