

Traumatic Brain Injury (TBI) Patient and Family Guidebook



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I am **GINA** your **G**uidebook **I**nformation **N**avigating **A**ssistant

Throughout this guidebook, I will provide information and education about traumatic brain injury care and treatment. I know that I will not have answers to all of your questions, but our incredible healthcare team is available to you and your family to answer all questions in real-time.

We are here for you.

Please keep the guidebook in your hospital room so that your healthcare team may add material specific to you. This guidebook is intended to be an introductory resource and to serve as part of your comprehensive rehabilitation program.

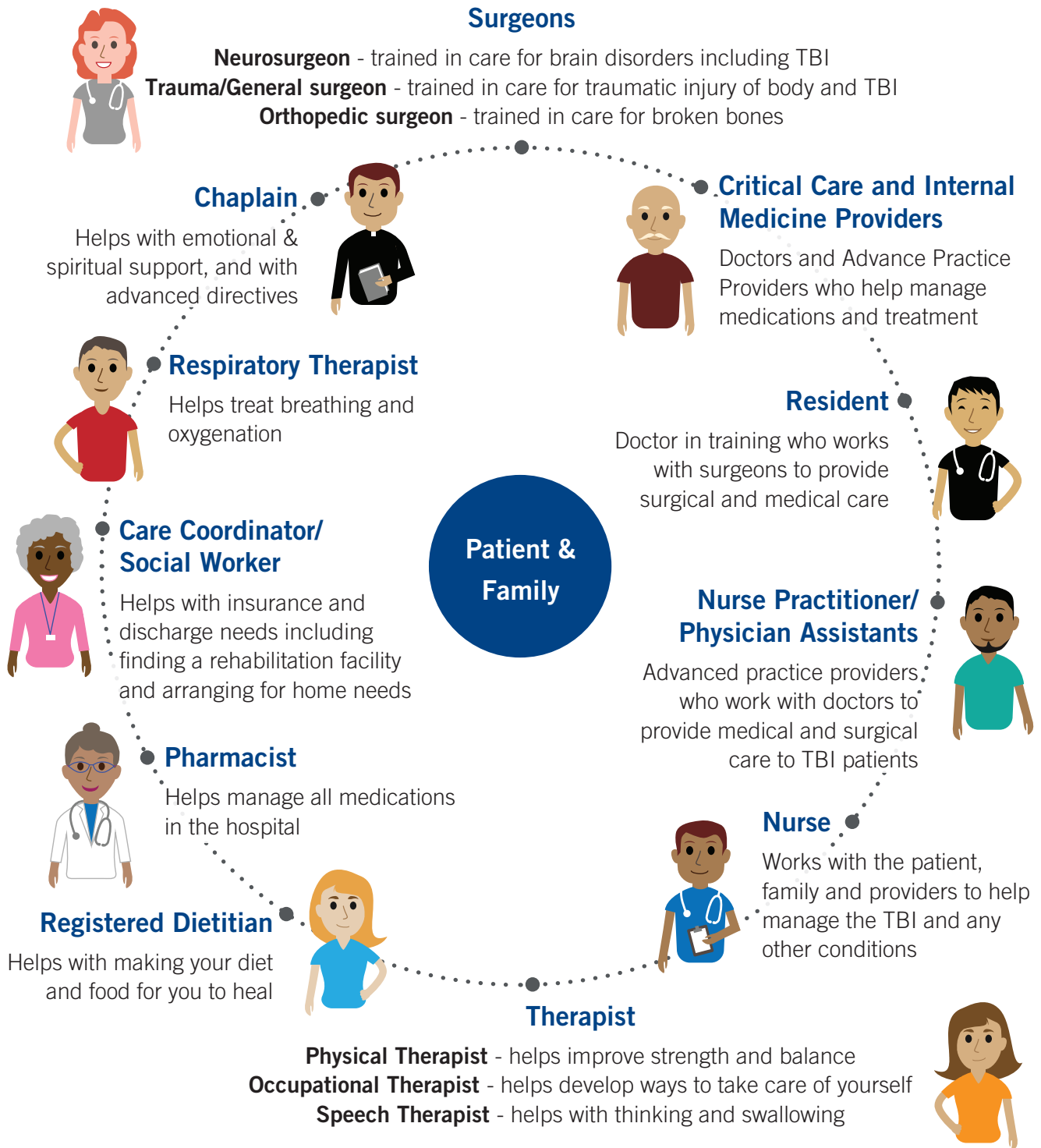
Please let us know if we can assist you in any way.

Traumatic Brain Injury (TBI) Patient and Family Guidebook

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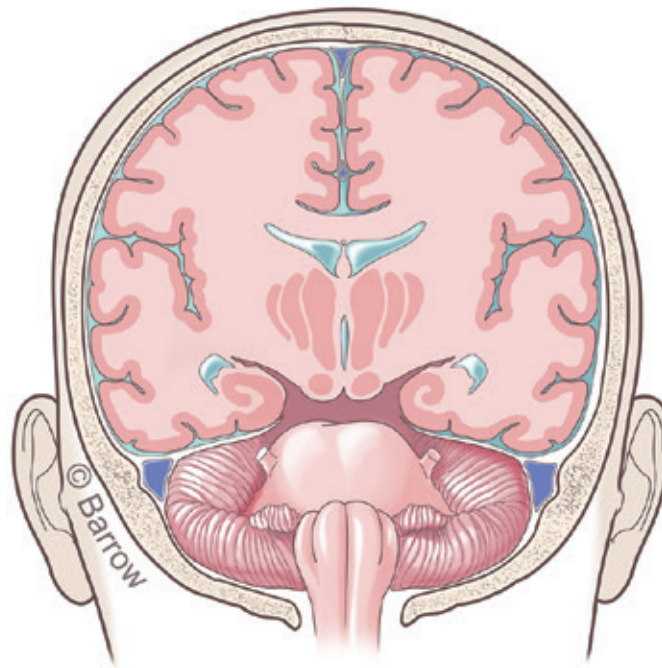
Meet Your Team



What Happens After TBI?

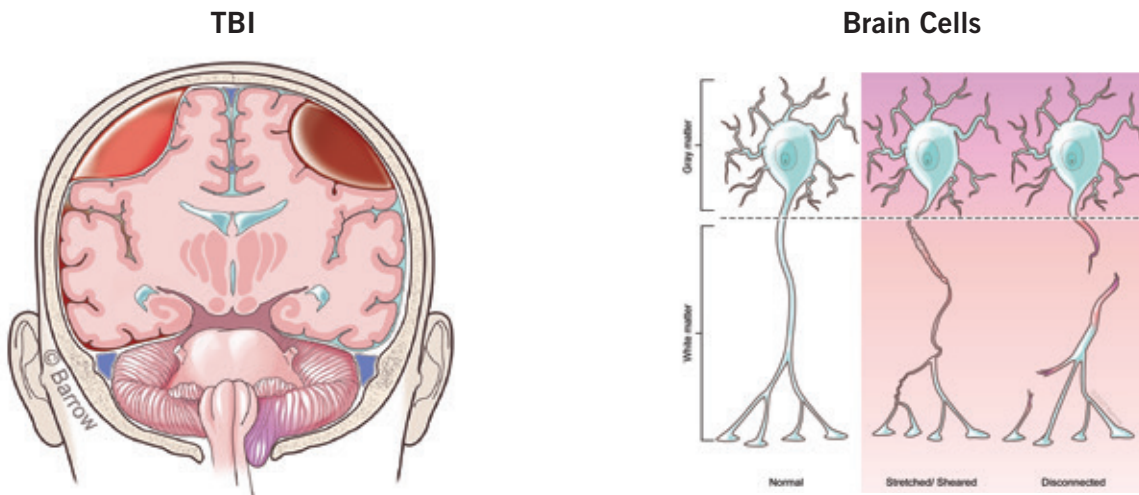
Normal Brain

The nerve cells or information connections in the brain send message to our body to control movement, sensations such as seeing, hearing, touching, feeling, and speaking along with our breathing, heartbeat, digestion, bowel, and bladder.

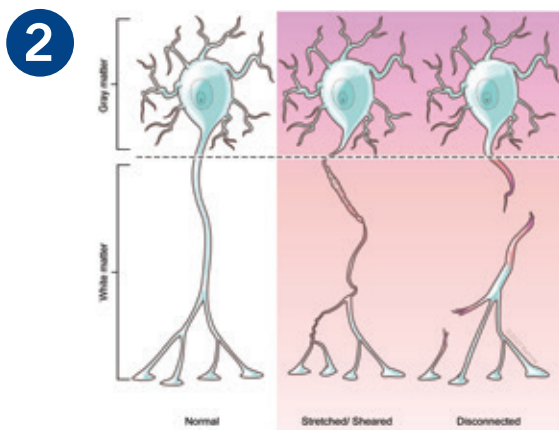
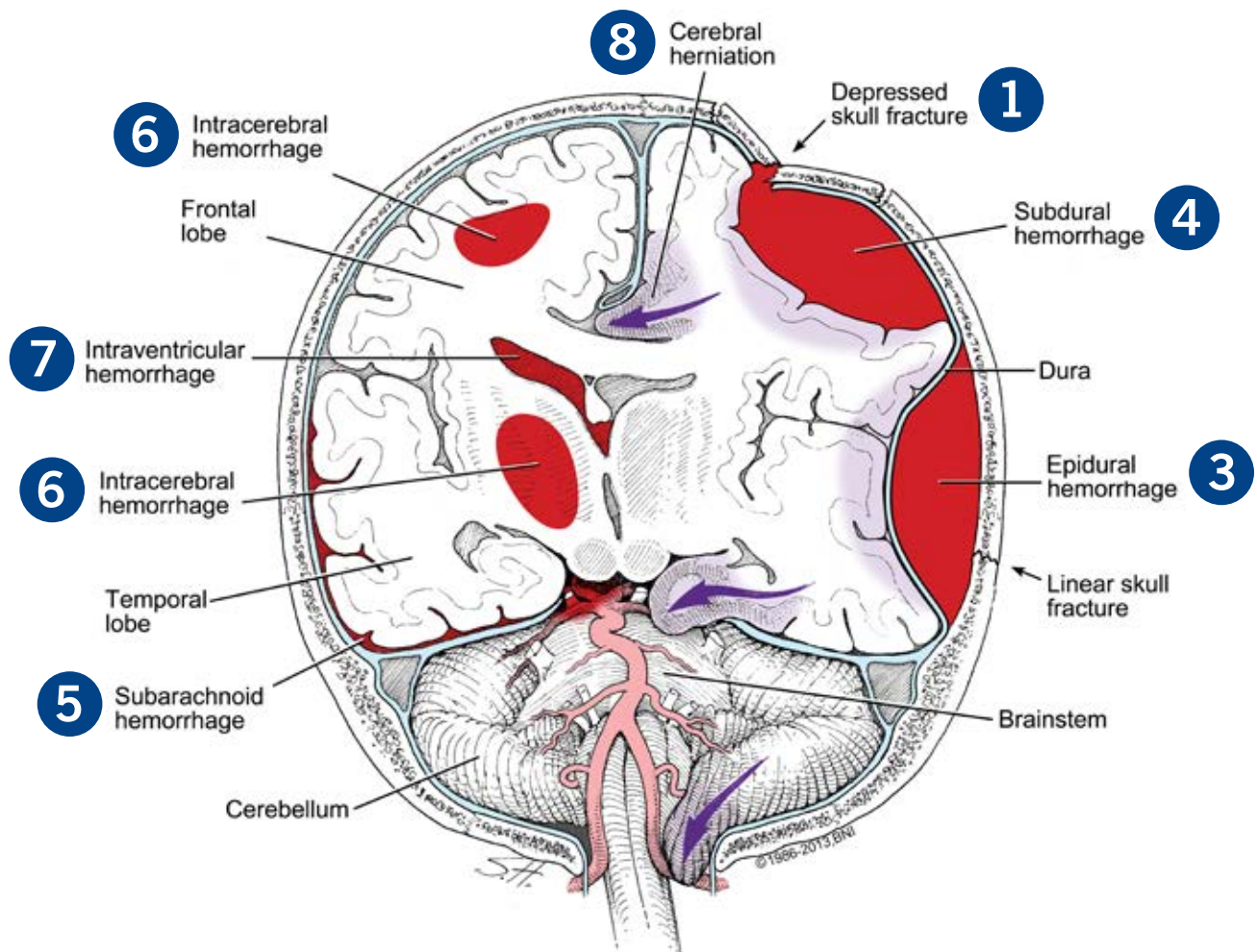


How Does Traumatic Brain Injury (TBI) Affect My Body?

TBI can change your normal brain function. Damage to the brain cells due to bleeding, tearing, brain swelling, or a broken skull can change the brain's ability to send messages to the body. The brain also cannot understand messages sent from the body. For example, the brain may not recognize if you are in pain.



What is My Injury?





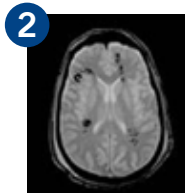
What is My Injury?



1

Skull fracture

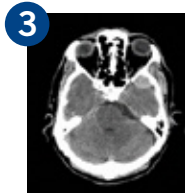
- Skull bone is broken
- Can be small break and brain stays in the skull
- Can be larger break and brain comes out of skull



2

Diffuse Axonal Injury (DAI)

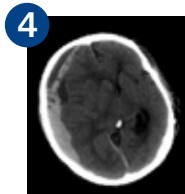
- Can be mild or severe brain injury
- Damage to the nerve connections that send messages to the body



3

Epidural Hematoma

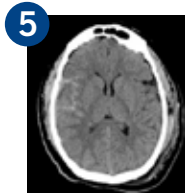
- Bleeding outside of brain (between the skull and the brain)
- May need surgery to remove if pressing down on brain
- May need other brain monitoring



4

Subdural Hematoma

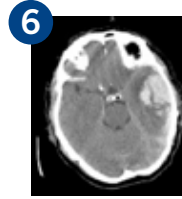
- Bleeding outside of brain (between the skull and the brain)
- Can happen at time of injury or forms slowly over weeks
- May need surgery to treat if pressing down on brain
- May need other brain monitoring



5

Subarachnoid Hemorrhage

- Bleeding outside of brain (between the skull and the brain)
- Injury that is not due to ruptured aneurysm
- May need other brain monitoring



6

Intracerebral Hemorrhage and/ or Brain Contusion (bruise)

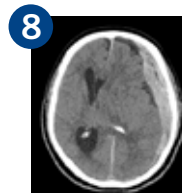
- Blood clot or bruises in the brain - can be in multiple places
- Can increase in size over days like bruises on the arms or legs
- May need other brain monitoring
- May need surgery to treat



7

Intraventricular Hemorrhage

- Blood clot in the spaces of the brain
- May need other brain monitoring or drain to prevent elevated pressure within the skull
- May need surgery to treat.



8

Herniation (Purple arrows)

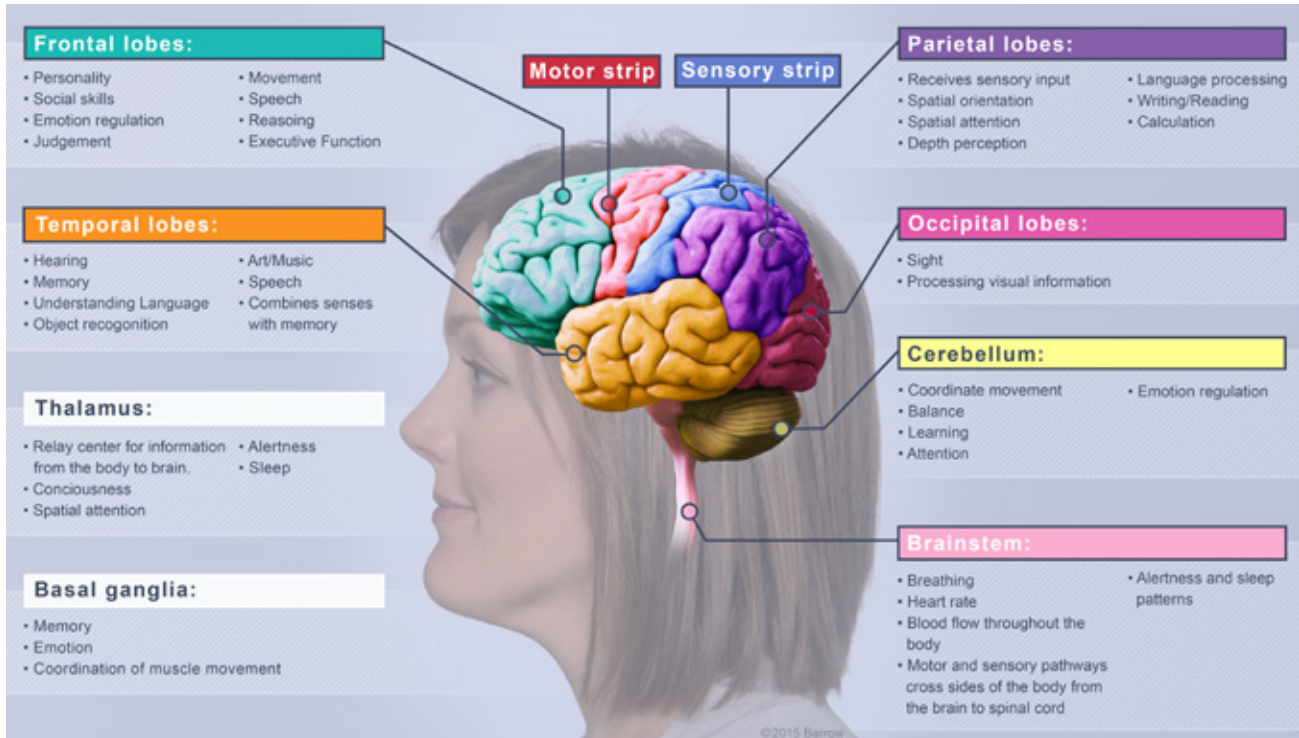
- Pressure from an injury moves the brain from its normal space in the skull
- Can cause other parts of the brain to be injured
- May need surgery to remove the pressure on the brain

9

Concussion

- No changes are seen on imaging.
- Symptom management

What Area of My Brain is Hurt?



Symptoms from a TBI depend on the severity of injury and the location of the injury in the brain.

Some areas of the brain are extremely small but necessary for life. Injury to these critical areas can sometimes lead to death.



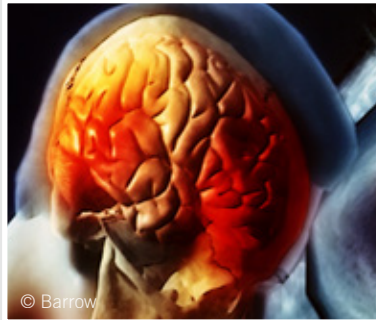
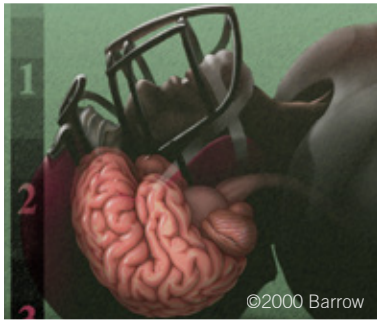
5 Issues That Can Happen After a TBI

1. Difficulty with thinking, memory, learning, making decisions and reasoning.
2. Behavior and emotion problems. You may be confused, agitated, sad, depressed, anxious or angry. You may yell out or try to hit others.
3. Strength and balance problems, as well as problems with walking or coordination.
4. You may have changes in your vision, hearing, taste, and be sensitive to light.
5. Headaches and pain, dizziness, nausea and vomiting, fatigue and tiredness, and sleeping problems.

CDC Chart to Congress

How Severe Is My Injury?

TBI can sometimes get worse before it gets better. Damage to the brain happens at the time of injury and can also continue in the following days to weeks due to swelling or bleeding in and around the brain.



Mild TBI

- May or may not lose consciousness.
- Aware of your environment but may be confused
- May need care in hospital
- Testing may show brain and skull as normal

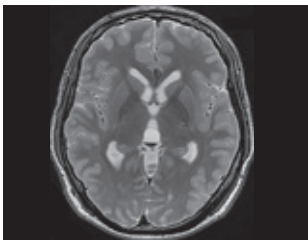
Moderate TBI

- May lose consciousness
- May not be aware of surroundings
- May have problems with strength, speech, and thinking
- May not be awake
- Will need care in hospital
- May need care in the intensive care unit
- Testing will show injury to brain or skull

Severe TBI

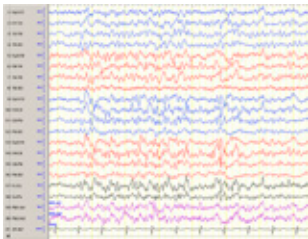
- Most amount of brain injury
- Not awake-comatose
- May have problems with strength, speech, and thinking
- Will need care in the intensive care unit
- Testing will show injury to brain or skull

What Tests Are Done?



Magnetic Resonance Imaging (MRI) and Computerized Tomography (CT)

Pictures of your brain using CT or MRI will be done to look for the place in the brain that is hurt. As you heal you may have more pictures taken to follow how you are healing.



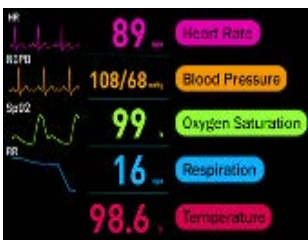
Electroencephalogram (EEG)

TBI can cause seizures. Sensor pads may be placed on the scalp and facial areas to look for seizures with an electroencephalogram (EEG). If you have seizures, you will be given medications to stop the seizures.



Blood Tests (Laboratory Tests)

Your blood will be drawn to measure lab values and provide treatment if needed.



Monitoring

Your heart rate and heart waveform, oxygenation, blood pressure, respirations, and temperature will be monitored.



Physical and Neurological Examination

Doctors, nurses, and therapists will ask you questions multiple times during the day and night to monitor your neurological status. They will also ask you follow instructions to test your thinking, strength, and coordination to determine treatment. This is how we make sure you are healing.

In the Hospital, What Happens to Me?



After coming in through the emergency department, you may be in the ICU or the telemetry (heart monitor) floor. Let's start with the 5 milestones you can expect after a TBI.

Milestone 1

ICU Care, Treatment, and Possible Brain Monitoring

The focus will be on your neurological examination and overall medical stability. You may need tubes and other monitors to keep you safe.

Milestone 2

Airway and Breathing

Your team will make sure you have enough oxygen and are breathing ok. You may require a breathing tube and or other tubes to give you oxygen.

Milestone 3

Heart, Blood Pressure, Movement, and Pain Management

Once your vital signs and neurological examination are stable you will be helped out of bed. We will give you pain medications if needed to keep you comfortable.

Milestone 4

Thinking and Consciousness

We continue supporting your recovery as your thinking and awareness of your surroundings improves.

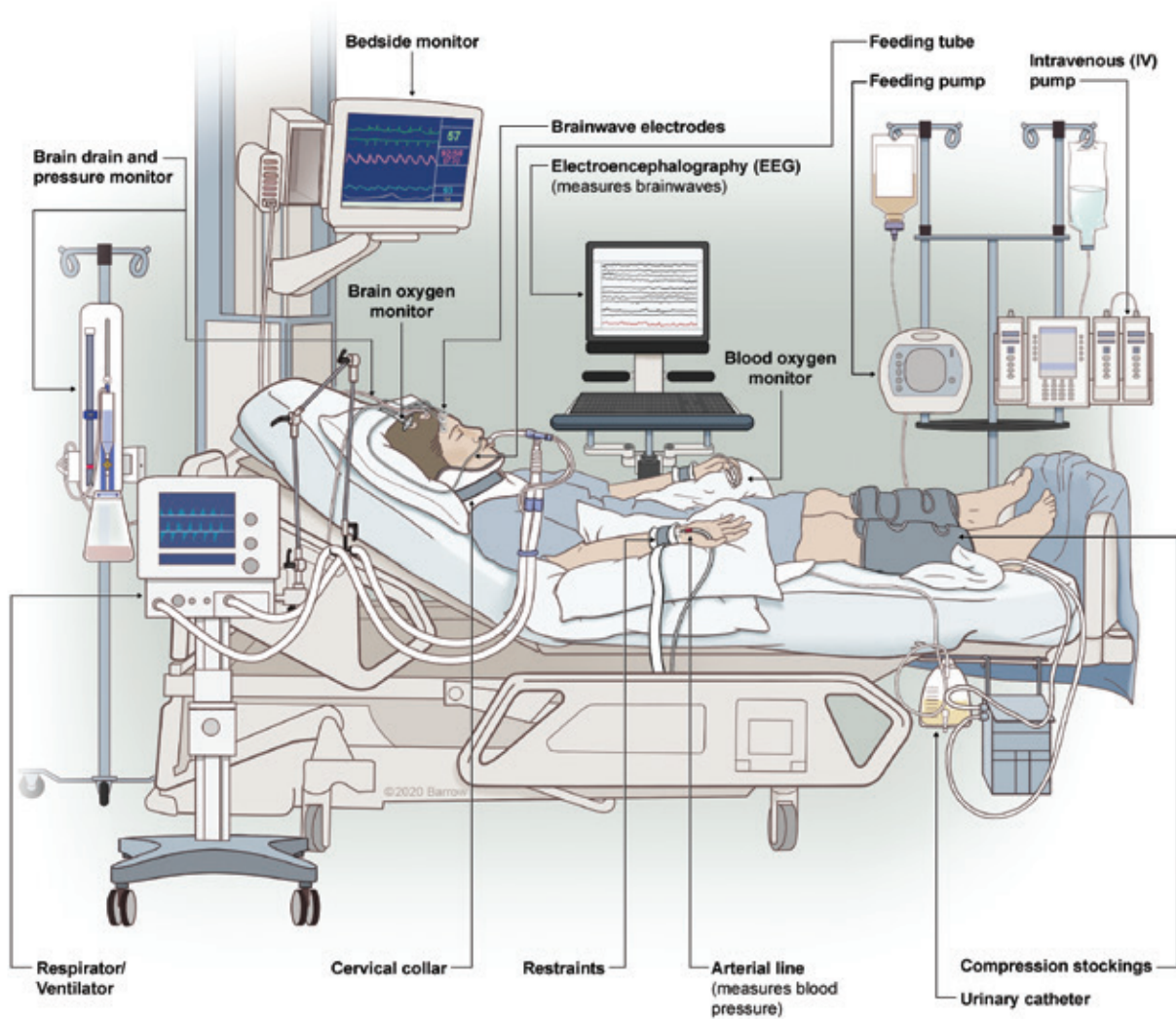
Milestone 5

Eating, Nutrition, and Toileting

We will make sure you have food to heal and that you are able to urinate and have bowel movements.

Milestone 1

Care, Treatment, and Brain Monitoring: What Happens to Me?



You may have many tubes and devices that help with your care and monitor your stability.

Your doctors, nurses, and respiratory therapists will show you what lines and machines you are using and may need in the future.

What Treatments are Used in the ICU?

Your team may use the following to treat pressure (swelling) in the brain:

Medical and Nursing Care

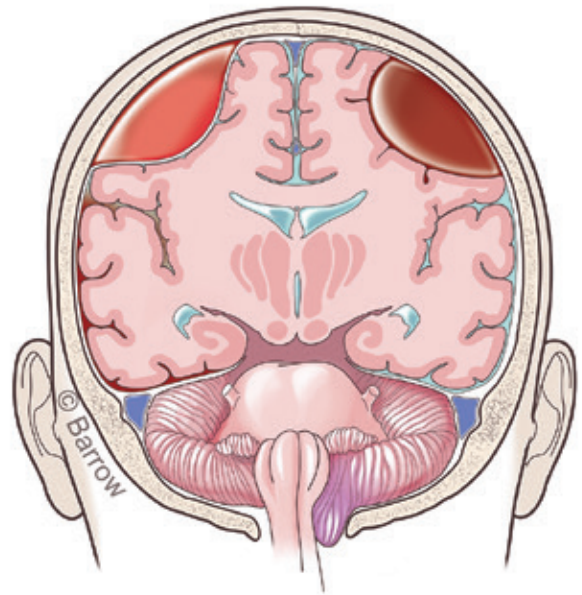
- Monitor neurological exam
- Medications and IV fluid management
- Keep vital signs and oxygenation normal
- Monitor brain with CT scans and/or MRIs
- Monitor lab values
- Prevent infection
- Treat seizures

ICP Monitoring

- Treat ICP above 22
- Draining excess fluid on the brain
- Keeping the head of the bed elevated to drain CSF
- Keep environment calm
- Promote rest

Surgery

- Remove blood clots within the brain
- Remove part of the skull so the brain has room to swell

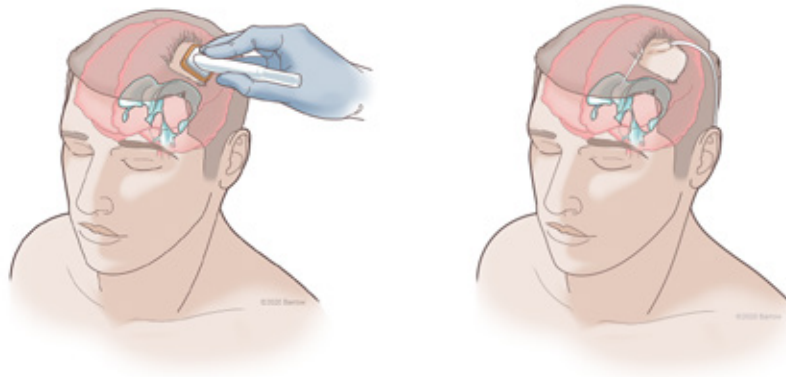


Brain Monitoring & Treatment

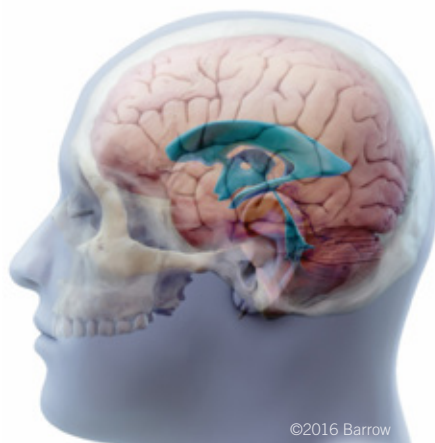


ICP monitoring may be done if you have a severe TBI.

The neurosurgeon will place an ICP monitor. This can be either a wire with a sensor in the brain or a drain called an external ventricular drain (EVD) that is placed into the ventricles of your brain.

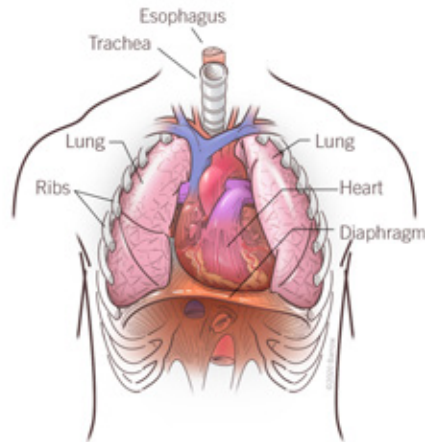


- ICP monitors help measure the pressure of the brain and drain cerebrospinal fluid (CSF) to prevent high pressure in your brain.
- Your doctors and nurses will keep your brain pressure below 22 while your brain is healing
- Monitoring ICP helps assess that the treatment plan is working, or help make changes to your treatment
- The monitors will be removed once ICPs are no longer high



Milestone 2

Airway and Breathing

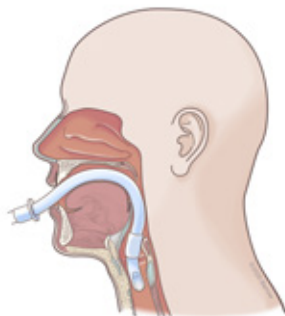


Lung and Heart Anatomy



If you are not breathing well, you may need a breathing tube inserted and connected to a breathing machine and oxygen (ventilator).

- The breathing tube and machine will be removed once you can safely breathe on your own.
- Some people need more time to be able to safely breathe on their own due to the severity of the brain injury, or they have other lung injury or infections. If you need the breathing tube for longer than a week, it may be removed from your mouth and placed in your neck. This is called a tracheostomy.
- Tracheostomies may be removed at a later time once you have recovered.



Breathing Tube



Tracheostomy

Milestone 3

Heart, Blood Pressure, Movement, and Pain Management



The brain needs a constant flow of blood to carry the oxygen and nutrients such as sugar (glucose) to feed your brain cells.

Your heart and blood pressure will be monitored using:

1. Heart monitor pads are placed on the chest to measure heart rate.
2. Blood pressure cuffs
3. If frequent blood pressure monitoring is needed, a sensor is placed in the artery of the wrist and connected to a blood pressure monitor.



Your nurses, physical, and occupational therapists will do the following to help with blood flow and other complication such a blood clot formation (Deep Vein Thrombosis - DVT):

- Sit you up in bed
- Get you out of bed with help; you may need to be slid from the bed to a specialty chair
- Move your arms and legs
- Use specialty compression stocking on your legs called SCDs (sequential compression device)
- Physical and occupational therapy work with you to get stronger, improve your balance, and help you eat, dress, and toilet.
- Pain medicines and supportive therapy will be used to help you be comfortable to get up out of bed and work with your therapists to recover



When you are in bed or out of bed, you may need the following for your safety:

- Restraints may be placed to keep you from pulling tubes
- Alarms may be placed on chairs to help prevent falls
- Helmets may be used for protection after surgery and part of the skull is removed






Milestone 4




Thinking and Consciousness



Rancho is a tool used to help monitor your thinking. Families and friends can help you during your recovery.

Always use a calm tone and voice:

Rancho Levels	What can family and friends do to help?
 <p>Level I: No Response No response to stimulation</p>  <p>Level II: Generalized Response Some response to stimulation</p>	<ul style="list-style-type: none"> • Talk to your family member in normal voice, tell where they are and what happened • Move arms and legs if ok with the nurse • Hold hands • Limit the number of visitors to 2-3 people at a time. • Keep the room calm and quiet. • Bring in favorite belongings and pictures • Give rest periods • Watch TV
 <p>Level III: Localized Response Awake on/off during the day. May recognize family and begin to respond inconsistently to simple questions with “yes” and “no” head nods.</p>	<ul style="list-style-type: none"> • All of above • Keep comments and questions short • Use 1 or 2 step directions at a time “can you turn your head and look at me?”
 <p>Level IV: Confused/Agitated May overreact and hit, scream, or use abusive language. This is due to confusion, feeling scared and not understanding what is happening. May be restrained.</p>	<ul style="list-style-type: none"> • Tell them where they are and what happened • Reassure they are safe • Allow as much movement as is safe • Do not force them to do things • Listen to what they wants to do and follow his lead, within safety limits. • Give breaks and change activities frequently.
 <p>Level V: Confused/Inappropriate May only able to pay attention for only a few minutes. Become overloaded and restless when tired or when there are too many people around.</p>	<ul style="list-style-type: none"> • Re-orient repeat and remind • Don't assume that he will remember what you tell him • Keep comments and questions short and simple • Help organize and get started on an activity • Give frequent rest periods.

Ranchos Levels	What can family and friends do to help?
 <p>Level VI: Confused/Appropriate</p> <p>May know they are hospitalized because of an injury, but will not understand all of the problems.</p> <p>May be more aware of physical problems than thinking problems and think that all will be fine as soon as they go home.</p>	<ul style="list-style-type: none"> • Repeat and discuss things that have happened during the day to help improve memory • Encourage participation in all therapies.
 <p>Level VII: Automatic/Appropriate</p> <p>May have problems with attention and be distracted. May have difficulty planning, starting, and following through with activities. May not realize how his thinking and memory problems may affect future plans and have rigid thinking.</p>  <p>Level VII: Purposeful/Appropriate</p> <p>May realize that there is a problem in thinking and memory and begin to compensate for problems. May begin to be more flexible and less rigid in their thinking.</p>	<ul style="list-style-type: none"> • Talk with them as an adult • Be careful when joking or using slang, because they may misunderstand the meaning • Do not criticize • Reassure that the problems are because of the TBI • Strongly encourage to continue with therapy • Be sure to check with the physician on restrictions concerning, driving, working, and other activities • Discourage from drinking or using drugs, due to medical complications • Talk about feelings • Educate

http://file.lacounty.gov/SDSInter/dhs/218115_RLOCFOriginalFamilyGuide-English.pdf



Milestone 5

Eating, Nutrition, and Toileting



After a TBI, swallowing ability may be impaired.

It may be unsafe for you to take food by mouth without risk of choking which puts you at risk for complications like aspiration of food into lungs and pneumonia.

- You may be too tired to eat enough food and get enough calories to heal.
- A speech language pathologist (SLP) will work with you to see if you are safe to swallow, and what kind of food you can have that is safe for you to eat.
- If you are unable to swallow safely or are too tired to eat, you may have a temporary feeding tube placed so liquid nutrition and medications may be given.
 - These feeding tubes are placed through the nose down into the stomach and small intestine. These tubes are used only in the hospital.
- If your swallow does not get better in the hospital, you may need the feeding tube placed directly into your stomach. These tubes can be in place for months or be permanent. The tube can be removed if you are able to eat and swallow safely.



Temporary Feeding Tube



Standard Feeding Tube



Low-Profile Feeding Tube



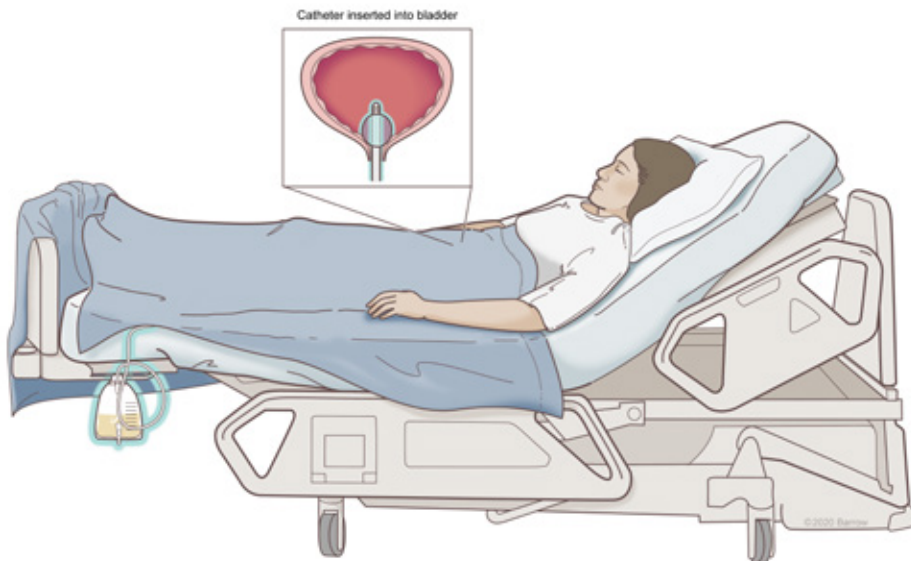
Registered dietitians are experts in nutrition and work with you and your team to determine what food will work best for you either by mouth or through the feeding tube.

Urinating and Bowel Movements

Urinating

Initially, you may have a tube in you bladder to drain and measure urine (a catheter).

- This urinary catheter tube is typically removed after a few days to prevent infection.
- After this, some people may be unable to empty their bladder of urine need scheduled catheterization every 4-6 hours.
- A bladder training schedule may be implemented that can be continued at home.



Bowels

Lack of physical movement and pain medications can cause constipation.

- This urinary catheter tube is typically removed after a few days to prevent infection.
- Your team will give you medications by mouth and rectally to help you have bowel movement
- Your registered dietitian will help with your diet.

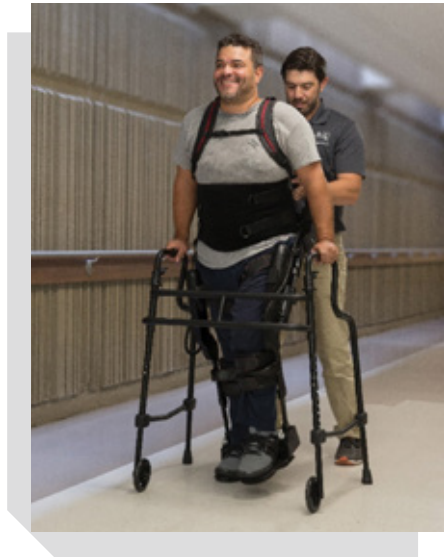
From the Hospital, What Happens Next?



As you become stable and leave the ICU, you may transfer to a regular hospital floor or a telemetry (heart monitored) floor for a few more days of monitoring.

The place you go after your discharge from the hospital can vary depending on your level of recovery and your insurance: Examples include the following:

- **Long-Term Acute Care Hospital**
When a person has stabilized but needs longer hospital care.
- **Acute Rehab Facility**
A person stays here and participates therapies for 3 hours per day. Typically for shorter duration of rehab needs.
- **Skilled Nursing Facility**
A person stays there and participates therapies for 1 2 hours per day. Typically, for longer duration of rehab needs.
- **Home with Family and/or Home Health**
Outpatient therapy and follow-up office appointments.



Care Coordinators are part of your team and will help with making your discharge plans and arrangements.

The care coordinators are experts and work/talk with your insurance to find the appropriate facility, home health agency, outpatient therapy that is covered under your insurance plan.

How Do I Monitor My Symptoms at Home?



Being vigilant about watching your symptoms when you go home is an important part of your care.

In some cases, bleeding can occur in the brain several days or weeks after a head injury. Or, in older persons, it can slowly develop over months, in some cases.

Let's review some things to watch for at home.

If your symptoms get worse, do not improve, or you have new symptoms you should call your doctor or go to the hospital.

Concerning symptoms include:

- Headaches that worsen and do not go away
- Throwing up (vomiting)
- Sudden trouble with talking, understanding, swallowing
- Sudden weakness, poor coordination, or not seeing clearly
- Loss of balance or passing out (fainting)
- Memory loss
- Feeling more tired than usual (drowsiness) or difficulty waking up
- Personality changes
- Seizures, often presenting as uncontrolled twitching or jerking
- Sustaining another injury
- Getting a fever
- Difficulty talking

What Can I Do to Stay Safe at Home?



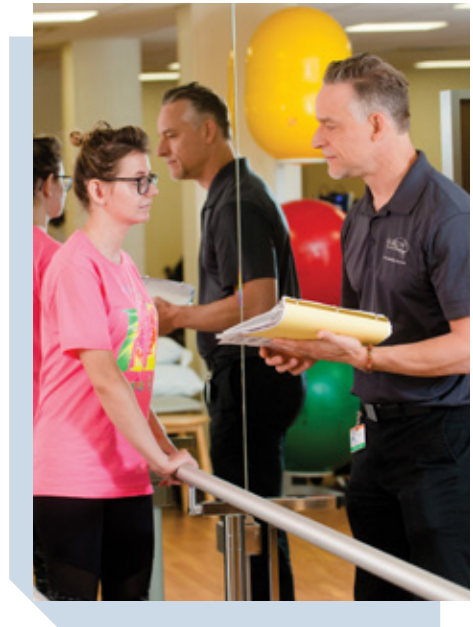
Knowing how to help yourself heal is an important part of going home.

Let's go over what you can do to help yourself heal.

This information will help you also understand what to avoid and what to do to stay safe and prevent further injury.

Help protect your brain!

- Follow up with all doctor and therapy appointments.
- Take prescribed medications.
- Prevent falls by clearing clutter or trip hazards.
 - Installing grab bars or using a walker may increase stability.
- Reduce sports injuries by wearing protective equipment.
 - A helmet approved by the American Society for Testing Materials (ASTM) important for high-risk activities.
- Always wear your seat belt and follow posted speed limits. Speed can affect the severity of an injury.
- Do not drink alcohol.
 - Alcohol affects the fluid balance of the body which can impair healing of the brain.
- Do not use products containing nicotine or tobacco.
 - These can increase blood pressure and change the way blood flows through the veins and arteries within your skull, and can slow or worsen your recovery.
- Check with your provider for what pain medications you can take. Do not take aspirin or Advil until your provider says you are safe to do so.
- If you are on prescribed blood thinning medications be sure your physicians know of your head injury and when they are safe to take.
- Do not drive until cleared to do so. Typically, you will not be cleared to drive when you first leave the hospital.
- Avoid high-risk activities that could cause head injuries, such as riding a bike or playing many sports.
- Do not take vitamins or herbal supplements without discussing with your provider. Some can prevent the blood from clotting and cause bleeding.



What Can I Do to Stay Safe at Home?

Manage health conditions such as high blood pressure or diabetes.

Elevated blood pressure (hypertension) can increase risk of increased bleeding while you are healing. Elevated blood sugar levels (hyperglycemia) can both affect blood flows through the vessels and impair wound healing.

- Consider safe smoking cessation options and avoid illegal drugs.
- Manage stress. This may include avoiding stressful situations or adding relaxation techniques.
- Exercise as directed.



Who Can I Call for Help, After Leaving the Hospital?



Here are a list of community resources to help you.

Call the number listed, or scan the QR code with your smartphone to be directly linked to the website.



Barrow Concussion and Brain Injury Center

(855) 993-6639

barrowneuro.org/centers-programs/concussion-brain-injury

Information on TBI, providers, and treatments available at Barrow Neurological Institute.



Brain Injury Association of America (BIAA)

Toll Free: (800) 444-6443 (V) (Family Helpline)

biausa.org

BIAA is a nonprofit, national advocacy organization that works to increase public awareness of brain injury, provide education and information about TBI and promote linkage to support groups and local resources through a toll-free Family Helpline.



Brain Injury Alliance Of Arizona

biaaz.org

Information and referral line, support groups, advocacy and other resources for survivors of brain injury in the state of Arizona.



Brain Trauma Foundation

braintrauma.org

The mission of BTF is to improve TBI patient outcomes worldwide by developing best practice guidelines, conducting clinical research, and educating medical professionals and consumers. BTF has developed scientific, evidence-based diagnostic and treatment guidelines to control secondary damage to the injured brain. Visitors to the website can view videos about coma, the coma checklist, and the BTF coma guidelines.



**Ability 360**

ability360.org/sports
 5031 E. Washington St., Phoenix, AZ 85034
 (602) 386-4566

Providing exceptional adaptive sports, recreation, aquatic, and fitness programs that promote the independence, health, and overall well-being of people with disabilities and their family members.

**Family Caregiver Alliance (FCA)**

Toll Free: (800) 445-8106
 caregiver.org

FCA offers programs at national, state, and local levels to support and sustain caregivers. Its goals include public advocacy for those with financial and emotional distress, direct services to family caregivers (in California), and the national distribution of information on caregiving and the care of people with chronic disabling conditions.

**Caregiver Action Network (CAN)**

Phone: (202) 454-3970
 caregiveraction.org

Non-profit organization providing education, peer support, and resources to family caregivers nationwide.

**ThinkFirst National Injury Prevention Foundation**

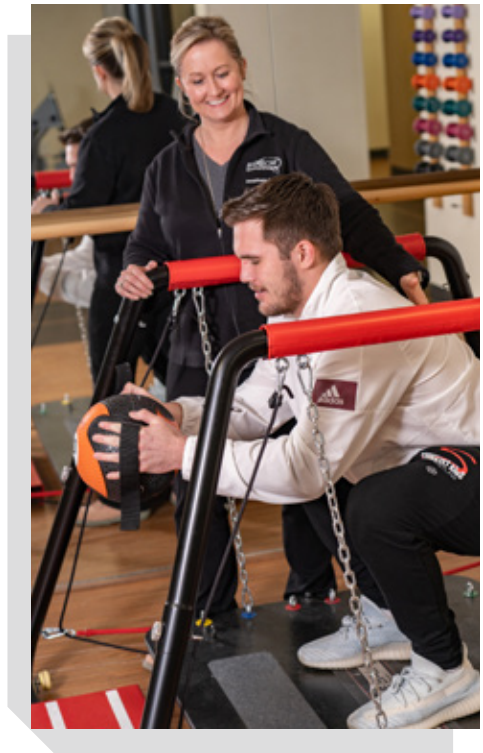
thinkfirst.org

ThinkFirst's Mission is to prevent brain, spinal cord and other traumatic injuries through education, research and advocacy.

**National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)**

acl.gov/about-acl/about-national-institute-disability-independent-living-and-rehabilitation-research

NIDILRR's mission is to generate new knowledge and to promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community, and to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.





The National Resource Center For Traumatic Brain Injury (NRCTBI)

Phone: (804) 828-3704

tbinrc.com

The NRCTBI develops a wide variety of assessment tools, intervention programs, and training programs. The web site contains a catalog of materials available for survivors, families, and professionals; “Chat with Pat” column that answers personal questions with compassion and practical advice; articles about recovering from a TBI; and related links.

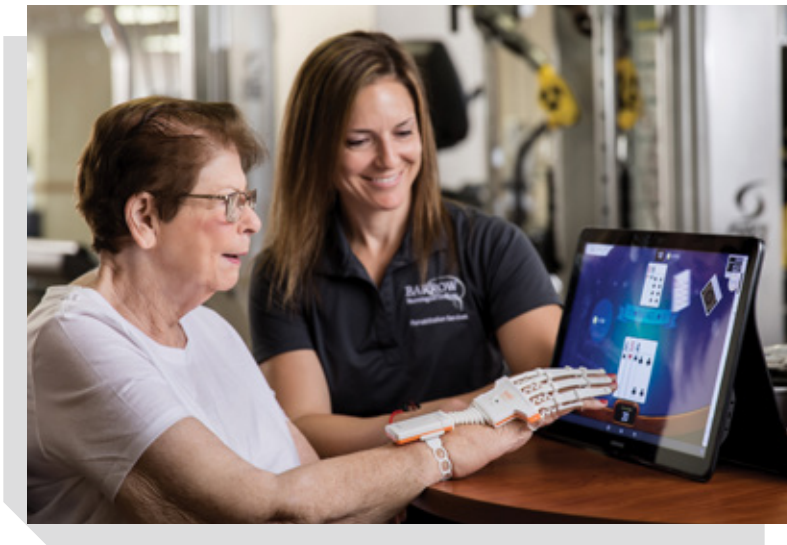


Brain Injury Resource Center

Phone: (206) 621-8558 (V)

headinjury.com

Provides callers with information on living with brain injury, including consultations and referrals to health care, legal professionals, and support groups. The website provides extensive information and resources on a wide variety of topics pertaining to brain injury.



My Tests, My Team, and My Progress

Tests Completed:

Affected Areas:

Plans:

My Tests, My Team, and My Progress

My Team Members:

Medications:

Activities:

References

Brain Trauma Foundation. Guidelines for the management of severe traumatic brain injury 4th Ed. 2016

Centers for Disease Control and Prevention. Community Health and Program Services (CHAPS): Health Disparities Among Racial/Ethnic Populations. Atlanta: U.S. Department of Health and Human Services,; 2008

Centers for Disease Control and Prevention (2019). Surveillance Report of Traumatic Brain Injury-related Emergency Department Visits, Hospitalizations, and Deaths—United States, 2014. Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. Downloaded January 28, 2021.

Family guide to the rancho levels of cognitive functioning. http://file.lacounty.gov/SDSInter/dhs/218115_RLOCFOriginalFamilyGuide-English.pdf P:\CDD\CDD0001FamilyGuidetoCognition.WPD 8/17/06

Hickey, JV. **The clinical practice of neurological and neurosurgical nursing.** 8th ed. 2020.





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