

Traumatic Brain Injury Patient and Family Handbook



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Treatment Information

Diagnosis: _____

Treatment Team

Staff Member Name	Specialty
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
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Procedures

Date	Procedure	Purpose
_____	_____	_____
_____	_____	_____
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_____	_____	_____
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_____	_____	_____

The Brain and Traumatic Brain Injury

Traumatic Brain Injury

Traumatic brain injury (TBI) is an injury to the brain from an external force. A TBI can cause a change in brain function.

Symptoms of a TBI can be mild, moderate, or severe depending on the extent of the damage to the brain.

Mild TBI is not always associated with loss of consciousness, but mild TBI can cause unconsciousness for a few seconds or minutes. Other symptoms of mild TBI include:

- headache
- confusion
- lightheadedness
- dizziness
- blurred vision or tired eyes
- ringing in the ears
- bad taste in the mouth
- fatigue or lethargy
- a change in sleep patterns
- behavioral or mood changes
- trouble with memory, concentration, attention, or thinking

Moderate or severe TBI can include all or some symptoms of a mild TBI, along with:

- headache that gets worse or does not go away
- nausea or repeated vomiting
- convulsions or seizures
- inability to awaken from sleep
- dilation of one or both pupils
- slurred speech
- weakness or numbness in the extremities
- loss of coordination
- increased confusion, restlessness, or agitation
- loss of consciousness

About The Brain

The brain controls important functions like movement, digestion, breathing, and sensory perception (for example, sight, touch, and taste). It also controls higher functions like thinking, learning, and emotions. To work properly, the brain needs to be protected from infections, trauma, and receive an adequate supply of oxygenated blood.

Although the brain gets some nutrition from cerebrospinal fluid (CSF), it is mainly nourished by oxygenated and nutrient-rich blood that is supplied by the left and right carotid arteries and vertebral arteries. Blood delivers essential substances that brain cells need to function.

Because of its importance to the body and its fragile, gelatin-like consistency, there are several layers of protection around the brain.

- **The skull** is the hard, bony covering that forms the outermost layer of protection for the brain.
- **The dura mater** is a tough, skin-like covering that is located between the skull and brain.
- **Cerebrospinal fluid (CSF)** is a clear, watery fluid that is produced in the ventricles, or hollow spaces in the center of the brain. CSF circulates outward from the ventricles, nourishing the brain and spinal cord. It also serves as a shock absorber that dissipates forces applied to the skull before they can be transferred to the brain.

Types of TBI

Skull fractures can occur anywhere in the skull and can be open or closed.

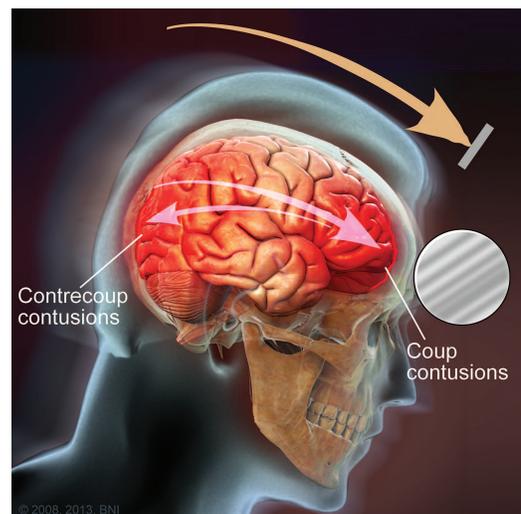
- A closed fracture is a break in the bone of the skull without a break in the skin or scalp.
- An open fracture is a break both in the bone of the skull and break in the skin or scalp. Open fractures exposing the brain to the external environment and can lead to infections of the central nervous system like meningitis if not treated. Bone fragments from an open fracture also can be pushed into the brain, resulting in a depressed fracture. Depressed fractures can damage brain tissue and may require surgery.

Contusion is bruising of the brain that occurs from the brain hitting the skull during trauma. There are two types of brain contusions:

1. **Coup contusions** occur at the site of direct impact to the skull.
2. **Contrecoup contusions** occur opposite from the site of direct impact and are the result of force transfer from the site of the injury to the opposite side of the brain.

Diffuse axonal injury is damage to the white matter (axons) of the brain. Violent force to the brain may stretch, tear, and twist the axons. Axons connect areas of the brain and spinal cord to each other and to the rest of the body. When they are damaged, messages from the brain or spinal cord to the rest of the body are slowed or lost. Swelling of the brain tissue may also occur, worsening the damage. The brain is not able to repair damaged axons, and there is no medical treatment that can restore their function. Therefore, treatment concentrates on limiting the damage by reducing swelling.

Concussion is an injury deep in the brain that can cause impaired consciousness. Concussion is considered a mild form of diffuse axonal injury and is sometimes called mild TBI.



Anoxic brain injury results from trauma—such as cardiac arrest or blood loss—that prevents oxygenated blood from reaching the brain. After approximately five minutes of oxygen deprivation, brain cells begin to die and anoxic brain injury occurs. Once brain cells die, they do not regenerate, although sometimes other surviving neurons can adapt and take over the functions formerly carried out by dead neurons. However, if this does not happen the neurological impairments caused by neuronal death are permanent.

Penetrating head injury describes gunshot wounds and other trauma originating from a projectile striking the skull. Higher speed projectiles tend to cause more damage to the brain because they penetrate deeper and deliver more energy.

Hematomas, also known as blood clots, result when a blood vessel is broken during an injury. If large enough, a hematoma can compress or shift the brain, and requires surgery.

Locations of Hematomas and Hemorrhages

Intracerebral hemorrhages or hematomas occur within brain tissue (Intra=within, the cerebrum).

Intraventricular hemorrhages or hematomas occur within the ventricles of the brain (Intra=within, the ventricle).

Epidural hematomas (EDH) are blood clots located between the skull and dura mater (Epi=on or upon, the dura). This blood clot may grow quickly and endanger the brain by putting pressure on it. Emergency surgery may be required to remove the blood clot.

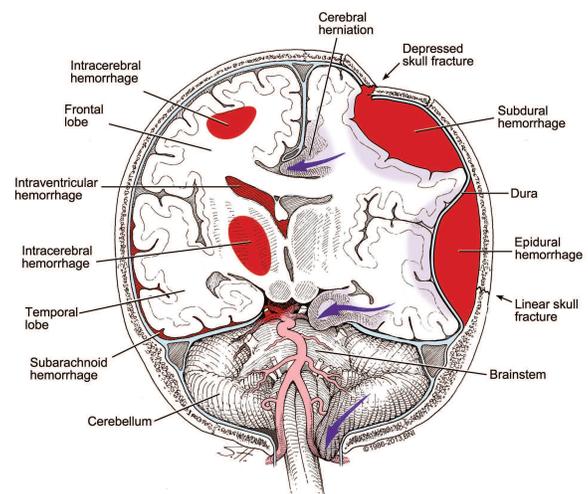
Subdural hematomas (SDH) are blood clots that form between the dura and the brain (Sub=below or underneath, the dura). SDH can occur acutely—at the time of the trauma—or they can form slowly over weeks to months (chronic SDH). Surgery may be required depending on the severity of the symptoms and the increase in intracranial pressure caused by the SDH.

Subarachnoid hemorrhage (SAH) is a clot that forms in the space between the brain and its arachnoid membrane (Sub- below or underneath, the arachnoid). The arachnoid membrane is a delicate surface that is attached to the underside of the dura mater.

The Delayed Effects of TBI

Brain damage occurs immediately after TBI. However, injury to the brain can also occur as a result of swelling or bleeding in and around the brain following the initial injury.

Increased intracranial pressure (ICP) is an increase in the pressure within the skull. The brain and its tissues, along with blood and cerebrospinal fluid (CSF), take up a given amount of space within the skull. Brain swelling, blockages in CSF circulation, and blood clots can all cause increased intracranial pressure, leading to further brain injury.



Brain anoxia or hypoxia is complete (anoxia) or partial (hypoxia) loss of oxygen to part or all of the brain. Anoxia or hypoxia can occur when blood flow to the brain stops or is reduced because of injury to the brain. Injuries to other parts of the body, especially the heart and lungs, can also cause hypoxia and anoxia of the brain.

Brain edema describes swelling of the brain, causing it to push against other contents in the skull. This is a major cause of brain injury, and can cause death if not treated.

Hydrocephalus is enlargement of the cerebral ventricles due to a blockage of CSF flow. Injuries that cause bleeding or swelling can distort and block the ducts that carry and circulate CSF within the central nervous system. When this happens, the cerebral ventricles can increase in size to accommodate the larger volume of CSF trapped within the skull. This can also lead to an increase in intracranial pressure (see above).

Brain herniation is when some structures of the brain move or are pushed across or through other structures of the skull due to very high ICP. Brain herniation is life threatening and can result in permanent neurological damage and disability.

Posttraumatic Amnesia (PTA)

Posttraumatic amnesia (PTA) is a period of confusion, memory impairment, or both, after an injury. Long term memory (such as address, date of birth, or significant historical events) often remains intact after TBI. There are two types of amnesia after TBI: retrograde and anterograde amnesia.

- **Retrograde amnesia** is partial or total loss of memory for the time period immediately before an injury. The span of retrograde amnesia can be as short as the few seconds before an injury, or as much as a month or more before the injury.
- **Anterograde amnesia** is reduced ability to store new memories after TBI. To determine if someone is experiencing PTA, the care team may ask the patient to recall information about their identity, location, and the date and time of accident or injury. In most rehabilitation programs, PTA is measured daily until the patient consistently and correctly answers questions without cues. It is important to avoid signing important documents and making critical decisions during the period of anterograde amnesia, as the patient may not be able to remember making that decision minutes or hours later.

The length of PTA is associated with severity of injury and long term recovery.

Behavior Management after a TBI

A patient's behavior may change after a TBI in ways that may cause difficulty for them and those caring for the patient. Behavioral problems after TBI can interfere with recovery, so it is important to reduce or eliminate these behaviors so that the patient can get the most out of rehabilitation.

Types of problematic behaviors seen after TBI include:

- **Impulsivity**—acting before thinking about the consequences of an action.
- **Disinhibition**—the loss of socially appropriate inhibitions.
- **Agitation**—strong emotional reaction to overstimulation (from too much noise, light, thought, or social interaction), frustration, confusion, or irritation.
- **Perseveration**—getting stuck on a certain thought, idea, or movement.
- **Confabulation**—the replacement of a gap in memory with false information that the patient believes is true.
- **Misperception**—holding a false, sometimes paranoid belief about the reality of events.

It is important to remember that:

- TBI patients do not behave in this way intentionally.
- Changes in behavior are a result of damage to the brain, most commonly the frontal and temporal lobes. People with frontal lobe injuries can become frustrated or act impulsively, exhibiting agitated or aggressive behaviors like yelling and cursing. They also may be overly suspicious, have problems with short term memory, and be easily disoriented.
- The team of therapists, doctors, and nurses will work together to create an appropriate behavior management program. All parties—patient and supporting cast—must work together to generate consistent responses and attitudes toward problem behaviors.
- Some tips for dealing with problem behaviors:
 - **Take frequency into account.** Episodes may be tolerable if they don't happen frequently, but may be difficult to cope with as frequency increases.
 - **Consider the severity of the behavior.** Mild arguments and episodes of frustration can be benign. If they escalate, try to identify the cause.
 - **Frequent and severe behaviors need to be addressed.** Continuing negative behavior can hinder recovery.
 - **Set up an environment that fosters success.** The environment should not be too stimulating (for example, not too many visitors at once, turn the television or music off when socializing or doing tasks) because overstimulation can increase confusion or agitation.
 - **Give direct and immediate feedback.** Cues and feedback should be simple and direct. Feedback can be positive (giving praise for doing something well) or negative (stopping a problem behavior). Disorientation, short-term memory loss, and difficulty with abstract thinking can complicate feedback, and people with brain injury may act out to avoid a difficult task or therapy.
 - **Remember age.** Addressing a patient in a way that is not appropriate for their age can

cause frustration and hostility.

- **Praise and encourage.** These interactions tend to help more than punishment.
- **Set realistic goals.** Break big, long-term goals into small, attainable goals.
- **Modify.** Change interactions as behavior improves and recovery progresses, but be as consistent as possible.
- **Encourage.** When working to eliminate or change a behavior, the behavior may get worse before it gets better. Encouragement can help speed this process.
- **Consult a doctor.** If negative behavior continues and disrupts the recovery plan, medications can be combined with the behavioral plan to jumpstart recovery.
- **Restrain.** Though unpleasant, these may be necessary if there is a threat of harm to self or others. Our staff can provide information about the least-restrictive options.

The Rancho Levels of Cognitive Functioning

The Rancho Levels of Cognitive Functioning is an evaluation tool used to identify patterns of behavior after a traumatic brain injury and help caregivers and all who interact with the patient understand what to make of this behavior and how to respond. It is a way to monitor how an individual is recovering from brain injury.

The scale identifies eight levels or stages that describe behavioral and cognitive deficits, allowing the treatment team to develop the most appropriate rehabilitation program for each individual. As the brain heals, it is possible for the person to improve and move up through the stages. Patients do not always demonstrate every behavior listed, and can even show characteristics of two stages at once. The eight levels are described briefly below. In addition, we have included some tips for what family members can do for their loved one at each of the eight stages.

Cognitive Level 1: No response

- A person at this level does not respond to sounds, sights, touch or movement. They appear to be in a deep sleep.

What can you do?

- It is unclear whether people in a coma can hear or understand what is said to them. Therefore, assume they do and, if you choose, talk to the person in a soft, relaxing voice about your day or any non-stressful topic.
- Touch the person. For example, hold their hand or wash their face with a damp cloth while explaining what you are doing, (i.e., “I’m going to hold your hand now”).

Cognitive Level 2: Generalized Response

- A person at this level will begin to slowly respond to sounds, sights, touch or movement, although they will likely remain asleep most of the time.
- They may respond slowly, inconsistently, or after a delay.
- Their responses may include chewing movements, sweating, breathing faster, moaning, moving, and increasing blood pressure.

What can you do?

- Continue suggestions from Level 1.
- If their eyes are open, ask them to look at you or something in the room.

- **Do not overstimulate.** Only provide the suggested stimuli for 5-15 minutes at a time, 3-4 times per day. Remember, rest is important to regaining cognitive function.
- Monitor their stress and frustration levels. If they are becoming frustrated or agitated, be patient and decrease the amount of stimuli.
- When talking to them, sit nearby so they can see you.
- Identify yourself every time you enter the room. For example, “Bob, it’s your sister Katie.”
- Ask non-stressful questions with ‘yes’ or ‘no’ answers as they become increasingly tolerant of stimuli.

Cognitive Level 3: Localized Response

- At this level, patients react more specifically to what they see, hear, or feel (i.e., withdrawing from pain, turning towards a sound).
- They remain awake for several minutes at a time.
- They may begin to follow some simple directions (i.e., “Squeeze my hand.”), but may not do so consistently.
- They may begin to recognize family and friends.

What can you do?

- Continue suggestions from Levels 1 and 2.
- Keep their room as quiet and soothing as possible. Limit visitors to two at a time.
- Bring in objects or photographs with meaning to help with memory.

Cognitive Level 4: Confused and Agitated

- Patients at this level can overreact to visual, audio, or touch stimuli by hitting, screaming, using abusive language, or thrashing. This reaction is due to confusion.
- They become easily agitated or aggressive.
- They are highly focused on basic needs (i.e., relieving pain, going back to bed).
- They have great difficulty following directions.
- They may not understand that your intent is to help.
- They are not able to pay attention or concentrate for more than a few seconds.

What can you do?

- Try not to take this behavior personally.
- Be patient. If agitation occurs, decrease the amount of stimuli. For example, turn off the TV and limit visitors.
- Keep distractions to a minimum.
- Gently correct them if they tell you the wrong information. However, do not argue if they insist on being correct.
- Help them with personal care so that they become more in touch with their environment. For example, help with dressing and grooming.

Cognitive Level 5: Confused and Inappropriate

- Patients at this level will be confused and have difficulty making sense of outside stimuli, although they will no longer be agitated.
- They are not oriented.

- They are restless when tired or over stimulated.
- They are not able to independently start or complete everyday activities (i.e., getting dressed and brushing teeth).

What can you do?

- Frustration is common. Encourage and reassure the patient as much as possible.
- Praise good behavior. Ignore inappropriate behavior unless safety is jeopardized.
- Try to redirect them if they are behaving inappropriately.
- Talk with them about family, friends, your day, and ask them questions. For example, “What happened in therapy today?” Give hints if they cannot remember.
- Talk with them about the problems that stem from their brain injury. Be open and honest. Reassure them that the goal of rehabilitation is to address these problem areas.
- Help them write down their daily schedule and other activities to help them improve memory and utilize compensations.

Cognitive Level 6: Confused and Appropriate

- A patient at this level will be somewhat confused because of memory and thinking problems (i.e., will remember they had visitors in the morning, but do not know what they talked about).
- They are able to follow a schedule with some assistance, but are confused by changes in routine.
- They may be able to pay attention for 30 minutes, but have trouble concentrating when there are multiple steps or distractions.
- They may be impulsive.

What can you do?

- Play cards or games that challenge the patient appropriately without causing frustration.
- Foster independence with daily activities by decreasing the amount of assistance you provide.
- Ask questions about events or conversations that just occurred to help improve their memory.
- Remember that rest is important.

Cognitive Level 7: Automatic and Appropriate

- A patient at this level follows a set schedule.
- They are able to do routine self care without assistance.
- They have problems planning, initiating, and following through with activities.
- They have trouble paying attention in distracting environments.
- They may not realize how their deficits impact future plans (i.e., expects to return to work right away despite having ongoing cognitive deficits).

What can you do?

- Encourage independence, but emphasize safety and good judgment.
- Continue to encourage the patient, especially when faced with new challenges.
- Be patient. Learning still takes time and changes will not occur overnight.
- Help them to focus on appropriate behavior during social interactions.

Cognitive Level 8: Purposeful and Appropriate

- A patient at this level may realize they have problems with thinking and memory.
- They begin to compensate for deficits.
- They are less rigid in thinking.
- They may be ready for job retraining or a driving evaluation.
- They are able to learn new things at a slower rate.
- They may show poor judgment in new situations.
- They have thinking problems that are not noticeable to people who did not know them before their injury.

What can you do?

- Encourage the patient to take responsibility for the majority of their daily activities of living if possible.
- Encourage and support the use of a memory book or schedule to help them track and complete tasks.
- During social interactions, observe their management, organization, stress, and frustration. If you notice difficulties, consult a doctor or therapist for guidance and strategies.

Information adapted from Ranchos Los Amigos National Rehabilitation Center:
<http://www.rancho.org>.

Treatment for TBI

The goal of care during hospitalization is to support, and maximize recovery. Stopping bleeding and stabilizing intracranial pressure (ICP) generally take priority. Adequate blood flow to the brain is maximized and patients are evaluated for any surgical needs.

Treatment Team

At Barrow Neurological Institute, we use a team approach that involves doctors and clinical staff with a wide range of expertise to evaluate and treat patients with traumatic brain injury. The treatment team for a TBI can include:

- physicians
- nurses
- respiratory therapists
- physical therapists
- occupational therapists
- speech therapists
- chaplains
- nutritionists
- case managers
- social workers
- family and friends

We encourage patients and their family to participate in their care. Asking questions is one of the most important things patients and families can do to understand their medical condition and treatment.

Emergency Department

Many patients begin treatment for a TBI in the Emergency Department (ED). Rapid assessment and triage take place in the ED. Diagnostic tests are performed and medication is administered to stabilize vital signs. Specialists such as neurosurgeons or trauma physicians may be contacted to assist and formulate a treatment plan to maximize wellness and prevent secondary injuries. Patients may be taken to radiology, surgery, or transferred to the intensive care unit or other part of the hospital, depending on their treatment needs.

Intensive Care Unit (ICU)

The ICU is designated for critically ill patients. Vital signs, airway, breathing, circulation, and neurological status are monitored closely using specialized monitoring equipment.

Key Team Members in the ICU

- **Physicians** from different specialties assist with treatment. It may be helpful to write down

the names and specialties of physicians for future use. It is most important to write down the name of the attending physician, as he or she directs treatment and coordinates the activities of all other specialty doctors.

- **Nurses** in the Barrow Neuroscience ICU typically care for two patients. The nurse administers all medications and collaborates with doctors and other medical staff to maximize wellness. Normal daily activities like nutrition, mobilization, and bowel and bladder training are started during an ICU stay by the nursing staff.
- **Respiratory therapists** work with the medical and nursing team to ensure that patients get enough oxygen. This may require mechanical ventilation, an oxygen mask, or nasal cannula.
- **Physical and occupational therapists** work with patients to maximize mobilization, range of motion, and splinting.
- **Speech therapists** may be consulted to evaluate swallowing and drinking.
- **Chaplains** are available for spiritual counsel and emotional support.

ICU Equipment

The following pieces of equipment may be used during an ICU stay:

- **Intracranial pressure (ICP) monitor** allows the care team to quickly detect and address high ICP.
- **Mechanical ventilator** pushes air into the lungs and pulls carbon dioxide and other waste gasses out of the lungs. It is used if a patient is not able to breathe on their own.
- **Electroencephalogram (EEG)** measures brain waves and is used to monitor seizure activity. It is also used if a patient is in a medically induced coma, to evaluate the effects medication on their brain.
- **Arterial lines** measure blood pressure and are typically placed in the radial artery, located in the wrist.
- **Central lines** may be placed in specific veins near the neck, chest, or elbow. They are used to administer intravenous (IV) fluids, blood products, and medications and to allow blood drawing for laboratory testing. They can also be used to deliver nutrients.
- **Intravenous (IV) lines** are usually placed in the arms and are used to administer fluids, medications, and blood products.
- **Sequential compression stockings** are wrapped around the legs and connected to a device that cyclically inflates and deflates them with air. They help prevent blood clots from forming in the legs due to lack of movement.
- **Nasogastric (NG) tube** is a small tube placed through the nose or mouth and into the stomach. They are used to help remove stomach secretions and reduce acid build up that can cause ulcers in case a TBI causes the stomach to stop functioning normally. If a patient is not able to chew or swallow, nutrition (tube feedings) may be administered through these tubes. When used this way, NG tubes are also referred to as feeding tubes. Feeding tubes are sometimes surgically inserted directly into the stomach or small intestine, bypassing the nose, mouth, and esophagus.

ICU Medications Types

- **Sedatives** are used to keep patients relaxed or unconscious and to reduce intracranial pressure. This class of medication wears off quickly when the dose is stopped, allowing rapid assessment of neurological status.
- **Analgesics**, or pain medications, are used to make sure that patients are comfortable and

- experience as little pain as possible.
- **Anticonvulsants** prevent seizures.
- **Diuretics** reduce the amount of water in brain cells and can be used to lessen intracranial pressure.
- **Antibiotics** treat bacterial infections of the brain that result from penetrating head injury or, rarely, surgical treatment or other interventions. It is also possible to develop infections from central lines and other invasive treatments.
- **Blood pressure medications** keep blood pressure from becoming too high (hypertension) or too low (hypotension).

Other Treatments

- **Suctioning** is done by nursing and respiratory staff members to prevent or treat pneumonia.
- **Tracheostomy** is used in conjunction with a ventilator and facilitates breathing directly through a surgically created hole in the trachea that bypasses the mouth and pharynx. A tracheostomy allows patients to cough up phlegm and makes it easier for nurses and respiratory therapists to clear blockages that may accumulate with long-term ventilator use.
- **Bowel and bladder care** will be facilitated using urinary catheters and diapers until the patient regains the ability to control them by themselves.
- **Oral and skin care** is monitored closely to reduce the risk of oral infection and bedsores.

Leaving the ICU

The team of nurses and doctors will discuss the next phase of treatment once a patient is well enough to leave the ICU. Discharge planning starts during the first days of hospitalization so that the patient and their family's needs are met. Nurse case managers and social workers provide guidance during this process.

When a patient has been cleared to leave the ICU, he or she may be transferred directly to another part of the hospital, to acute or subacute rehabilitation, or to a long-term acute care hospital. There is no predetermined timeframe for transfer from the ICU to the next level of care. If transferring within the hospital, the patient will continue to be followed by the same attending physician but may have other consulting physicians that assist with care.

A patient may be transferred to the telemetry unit if continued heart monitoring is required. The nurse-to-patient ratio on that floor is typically 4-5 patients per nurse. The patient will continue to be seen by therapists to progress toward transfer to a rehabilitation unit. Patients who do not need continued heart monitoring are generally transferred to an acute care floor before moving to rehabilitation.

Family FAQs

What is the best way to communicate with the doctor to find out the condition of my loved one?

Doctors usually make their rounds early in the morning. Having someone at the bedside with prepared questions ensures that you will get the answers you need. Residents, nursing staff, and nurse practitioners can also help answer questions, along with the staff at the attending physician's office. Keep in mind that the nursing staff spends more time in contact with a patient than doctors do, and can be an excellent resource for questions and concerns.

How long before my loved one gets better? What will they be like?

This is impossible to determine without neurological evaluation. The professionals listed above are great resources for answering specific questions regarding the prognosis of your loved one.

Who helps with insurance and finance questions?

The nurse case manager and social worker will assist with financial arrangements.

What can I do to help at the bedside?

The medical team and bedside nurse can give excellent guidance in this area. Feel free to ask any questions.

I am not coping well. Whom can I talk to?

Watching a loved one endure any illness can cause fear, anxiety, anger, restlessness, sadness, and many other emotions. Chaplain Services is an excellent resource when you need an attentive listener. They are available around the clock and can be reached by dialing '0' for the hospital operator and ask for Chaplain Services.

What are some coping strategies?

- Write down important questions to ask the medical team in a journal or notebook.
- Create a caring bridge website or phone tree to update the condition of your loved one. This will help to reduce the number of calls.
- Rotate family visits to ensure that everybody gets enough rest. It is important to accept help and express your feelings. Just as it takes a team of doctors and nurses to care for your loved one, it often takes a team effort from family and friends to make your loved one feel cared for.

I am afraid and don't know what the next step is for care. Who can help me?

A social worker and nurse case manager will work with you, your loved one's insurance company, and the medical team to assist with discharge and treatment planning.

Recovery and Rehabilitation

Recovery Process

Generally, the process of recovering from a TBI can be grouped into 4 stages:

- **Stage 1: Unresponsiveness or coma.** The patient has only reflexive responses that are not purposeful and do not require thought. They may move their arms and legs randomly or may respond to pain by extending or flexing their arms or legs.
- **Stage 2: Early responses.** The patient may gradually start to follow commands such as sticking out their tongue or react to other senses such as gentle touch, sound, or light.
- **Stage 3: Agitation and confusion.** As activity increases in the brain, patients may experience difficulty with memory and emotion. They may become agitated and lash out at those around them. Wrist, ankle, and other soft restraints may be utilized to keep them safe and to prevent them from removing tubes and lines. Sedatives may be administered to help keep them calm and promote sleep during the night. This stage can be very frightening for both the patient and the family, but it is temporary and a normal reaction to the stress put on the brain. At this stage, the patient may be transferred to a rehabilitation facility
- **Stage 4: Higher level responses.** It is likely that the patient will have been moved to a rehabilitation facility by this stage. They are now able to do routine tasks and start to make decisions. They may continue to have problems with insight, judgment and memory. Stressful situations can be more difficult, and there may be personality changes.

Rehabilitation Process

After a patient is discharged from the hospital, they will probably need continued rehabilitation to recover from their TBI. A team of physicians, nurses, therapists, and other professionals will help the patient regain their greatest degree of independence. Keep in mind that the best thing for each patient is to be at the appropriate level of care, not the most intensive. Early in the process of recovering from a TBI, a patient may not be ready for an intensive program, and overexertion could result in fatigue and feelings of hopelessness.

The experience in rehabilitation will be different from acute care and the ICU. Once in rehabilitation, the goal is to maximize each patient's independence. As such, patients are encouraged to do as much for themselves as possible. The family's participation is also encouraged, particularly if they will be assisting the patient after discharge.

The Rehabilitation Team

- **Rehabilitation doctor**, also known as a physiatrist, orders medications and tests, consults with other doctors, and oversees each patient's rehabilitation program.
- **Rehabilitation nurses** administer medications, implement doctors' orders, monitor vital signs, anticipate complications, and chart the patient's progress.
- **Rehabilitation technicians** help patients get in and out of bed, go to the bathroom, and perform daily care activities.

- **Physical therapists (PT)** help improve patient's mobility. They also address endurance, balance, sensation, and strength, along with providing family education.
- **Occupational therapists (OT)** help improve independence in cooking, bathing, using the bathroom, and other activities of daily living. OTs help patients regain coordinated use of their arms and also help patients relearn the cognitive skills they need to perform everyday tasks.
- **Speech and language pathologists (SLP)** assist with speaking skills, along with swallowing, language, and cognition.
- **Therapeutic recreation specialists (TR)** discuss hobbies and interests with each patient and try to incorporate those activities into a rehabilitation program. Patients may be able to go on outings to local restaurants or other activities, and may also participate in aquatic therapy.
- **Case managers or social workers (CM/SW)** coordinate with a patient's insurance company, work with each patient and their family on discharge plans, order necessary equipment and outpatient services following inpatient rehabilitation, and help the family cope with the demands of a neurorehabilitation program.
- **Dietitians** ensure that each patient gets adequate nutrition and help with any issues that stem from lack of appetite or difficulty eating.
- **Neuropsychologists** can test what changes have occurred in thinking, behavior, or emotions after a TBI. Neuropsychologists use this information to educate the patient and their family, to conduct cognitive retraining, to implement strategies to manage behavior after an injury, and to help develop a treatment and discharge plan.
- **Respiratory therapists** improve airway function and help patients breathe more easily.

Levels of Rehabilitation Services

- **Acute hospital care** is crucial and ideally should start in the ICU. Early rehabilitation can reduce complications and shorten a patient's hospital stay.
- **Subacute rehabilitation** occurs in a skilled nursing facility. Therapy may be offered daily, but tends to be less intense than acute rehabilitation. Nurses are always on site, but physician visits may only occur weekly. Subacute rehabilitation is ideal if the patient is minimally conscious or if they are unable to tolerate the intensity required by acute rehabilitation. They may be able to transition to acute rehabilitation once recovery progresses.
- **Acute rehabilitation care** occurs in an inpatient rehabilitation center after discharge from the hospital. This rehabilitation involves physical, occupational, and speech therapy services for a minimum of 3 hours per day, 5 days per week.
- **Outpatient rehabilitation** therapy programs usually involve 2-3 sessions per week in a clinical setting. If a patient is not able to leave their house, they may be eligible to receive some limited services in their home.
- **Day treatment** is an intensive rehabilitation program, typically provided in a clinical setting. Most programs focus on either return to home independence or return to work or school skills. Day treatment may involve up to 5 sessions per week.

Acute Rehabilitation Admission, Discharge, Transition Criteria

Criteria for admission to an acute rehabilitation facility includes, but is not limited to, the following. The patient:

- Should be able to tolerate and participate in at least 3 hours of therapy per day, for a minimum of 5 days per week
- Requires daily physician visits
- Requires 24-hour rehabilitation nursing

- Has a plan for discharge to a community setting
- Must be able to demonstrate measureable progress towards identified discharge goals

Discharge planning will begin after admission to acute rehabilitation to make a patient's transition to home less stressful.

Patients are deemed ready for discharge when their medical needs can be met in a less-skilled setting; meaning that they do not require daily visits from a physician or 24-hour nursing care. However, most patients discharged from the acute rehab unit after a TBI will require some level of assistance or supervision after going home.

The patient's family will need to participate in family training and education so they can learn the skills needed to assist their loved one. If a determination is made that a patient's family is unable to provide the care required, it will be necessary to facilitate a transfer to a skilled nursing facility.

Patient FAQs: Acute Rehabilitation

How long will I stay in acute rehabilitation?

The factors that determine your length of stay include, but are not limited to:

- your ability to participate in 3 hours of therapy per day
- your ability to demonstrate progress towards identified goals
- whether or not you need ongoing daily physician visits and 24-hour nursing care
- having a discharge plan in place

The *average* length of stay on the acute rehabilitation unit is 2-3 weeks.

Will I stay in acute rehabilitation until I am totally independent and ready to return to normal activities of daily living?

Not necessarily. Although it might seem ideal to stay until you are fully independent, it is often hard to keep motivated during a long hospital stay. Transitioning to outpatient rehabilitation offers more intense therapy and a real environment. There you can work on using your new skills rather than depending on nurses and staff.

What if my family cannot provide the 24-hour supervision that is recommended after discharge?

Most TBI survivors have cognitive impairments that require supervision. Unfortunately, there is no way to predict how long you will require supervision in the home setting. You will need to work with your physician and care team to determine when it is appropriate to reduce supervision. You can also work with our social worker to explore options for supervision in the home.

What should I expect of my caregivers?

Family members and caregivers are encouraged to participate in therapy and nursing care so they can help with your transition out of acute rehabilitation. Sometimes, however, the presence of a loved one may interfere with your ability to focus on therapy, and your care team may request that you temporarily limit visitations.

Your family members or caregivers may be asked to participate in formal family training a few days before you are discharged. This training may be longer if you require more complex care.

Am I allowed to leave the rehabilitation unit before I am discharged?

When you are deemed medically and behaviorally stable you can participate in community outings with therapists. Only your doctors and nurses can determine if you have reached this point in your recovery.

Can my visitors spend the night with me?

This is determined on a case-by-case basis. Please speak to the unit manager if you want an overnight visitor.

What about restraints?

Restraints may be used if you are a fall risk or if you demonstrate unsafe behavior. Our staff will always use the least-restrictive restraint that still ensures your safety. Restraints are never used as punishment or for staff convenience.

What about helmets?

You may need to wear a helmet if your treatment involved removing part of your skull, leaving your brain unprotected in that spot.

Outpatient Rehabilitation

Some outpatient facilities specialize in neurological rehabilitation. It is important to make sure that the facility chosen understands brain injury and has experience working with TBI patients.

Outpatient rehabilitation typically involves 2-3 sessions per week. During each session, the patient will spend an hour each doing physical therapy, occupational therapy, and speech therapy. The goals of these therapies include achieving greater independence in performing daily responsibilities in the home, returning to school or work, and resuming recreational activities.

The length of outpatient services will be dependent patient goals, participation, severity of the injury, and insurance plan coverage.

The Role of the Caregiver

- Caregivers may need to help schedule appointments, manage prescriptions, and arrange transportation to and from sessions.
- Caregivers may need to provide medical and social history, set goals, and emphasize activities that are important to the patient.
- The rehabilitation staff, with patient input, will help determine how often the caregiver should attend therapy.
- Caregivers will need to help with “homework” activities.
- Caregivers should be emotionally supportive and help seek out additional means of emotional support.

24-hour Supervision

A physician may recommend 24-hour supervision after discharge due to cognitive or physical impairments.

Things to consider when reviewing the 24-hour supervision requirement:

- Patient judgment. Would the patient respond appropriately to a stranger at the door or when presented with a small kitchen fire or other potential emergency?
- Using the bathroom. Can the patient get to the bathroom safely on their own?
- Patient insight. Can the patient recognize any limitations and how they affect daily activities?

Day Treatment Programs

Day treatment programs provide an intensive therapy program for adults and older adolescents recovering from TBI. Day treatment programs typically are higher intensity than traditional outpatient therapies.

At Barrow, our day program is administered through the Center for Transitional Neurorehabilitation, or CTN. CTN houses two main programs: the Home Independence Program and the Work and School Reentry Program. Patients can attend the program up to 5 days per week.

Home Independence Program

This program helps patients become independent at home and in the community by teaching how to:

- walk safely, with or without an assistive device
- move safely in a wheelchair
- communicate clearly
- conduct daily activities safely in the home and community
- become as productive as possible at home
- remain unsupervised from 4 to 24 hours per day
- adjust socially

School Reentry Program

The School Reentry Program facilitates a return to academics. CTN prepares students differently depending on what level of education they are returning to:

To return to secondary school (college or university):

- Patients should register with their university resource center for students with disabilities. These centers can provide accommodations such as extra time for tests and note takers. Patients will need to submit documentation of a TBI to confirm eligibility.
- Patients should consider taking an online class as a stepping stone to returning to a community college or university. Taking a class online allows therapists to monitor learning styles, develop compensatory strategies, and support a patient's academic career from a treatment environment.

To return to middle school or high school:

- Speech language pathologist or parents should set up a meeting with the school district to determine patient needs and collaborate on a return to school.

- The school will develop an individualized educational plan (IEP) if the patient demonstrates functional impairments that affect academic performance. If the patient does not qualify for an IEP, the school can develop a “504”. Section 504 of the Rehabilitation Act and the Americans with Disabilities Act requires that accommodations and modifications be implemented to level the playing field for students with disabilities. This grants specific accommodations (i.e., extra time for tests).
- Homework may be arranged before transition back into the classroom.
- The school may approve therapists to help set up behavioral plans and implement compensatory techniques on the patient’s behalf. The therapist may observe the patient in the classroom and exchange information with teachers.

Work Reentry Program

- The Work Reentry Program helps patients become productive through employment or volunteer work.
- Patients may start in a work or volunteer trial designed to help develop important work skills. Therapists will supervise this trial and assist with compensating for any disabilities.
- Before returning to work, patients must obtain medical clearance. The patient’s psychiatrist will set restrictions on the length and number of shifts.
- If the employer agrees, a job coach may accompany the patient to work.
- Patients will need to educate their employer on limitations and the compensations they require.

If a patient is not able to return to their former position, they may be able to apply to an alternative position that is more suited to their abilities. For assistance in returning to an alternative position, maintaining current employment, or exploring options for retraining, contact the Arizona Rehabilitation Service Administration. Information can be found on their website at https://www.azdes.gov/rehabilitation_services/

If a patient cannot return to work within 12 months of a TBI, they may want to apply for Social Security Disability benefits. To learn more about Supplemental Security Income (SSI) or Social Security Disability Income (SSDI), visit www.ssa.gov or call 1-800-772-1213.

Return to Driving

Getting back on the road is often a goal of TBI and SCI rehabilitation. However, impairments like muscle weakness, vision changes, slower reaction times, and cognitive problems can require a driving evaluation.

The State of Arizona requires that someone notify the MVD if there has been a change in their medical status that could impact their ability to safely operate a vehicle. It is each person’s responsibility to notify the MVD and failure to do so could result in criminal consequences and civil liability in the event of an accident.

To initiate the return to driving process, patients should talk with their doctor about what will be required to clear them for driving. The physician can ascertain if they are ready to start driving again and provide information on where to go for a driving evaluation.

Once all the required evaluations are done, the physician will review the results to see if the patient is fit to drive. If the patient is ready to resume driving, he or she along with their doctor will collaborate with the MVD to get the appropriate documentation and administrative steps completed.

For more information on the return to driving process, contact the Medical Review Board for the MVD at <http://www.azdot.gov/mvd/MedicalReview/MedicalReviewProgram.asp> or call (602) 771-2460.

Patient FAQ: Post-acute Rehabilitation

What rehabilitation services do I qualify for if I am on AHCCCS?

Outpatient physical therapy is the only benefit covered by AHCCCS if you are over 21 years old. Occupational and speech therapy services are covered if you are under 21 years old.

My family member is unable to bring me to therapy. What are my transportation options?

Transportation services vary by municipality. Phoenix Valley Metro can help you identify your options. You can call them at (602) 253-5000 or visit their website: <http://www.valleymetro.org/>.

What questions should I ask my insurance company about my outpatient rehabilitation benefits?

The following are some good questions to ask:

- How many visits per calendar year are covered for physical, occupational, and speech therapy?
- If the visits are a combined amount, does each session count as a visit, or if I see all three disciplines on the same day does it count as one visit?
- If I need more than the allotted visits per calendar year, is there a way to request more or appeal the ending of coverage?
- Do I have a copay?
- Is the facility I've chosen in my network of covered facilities?

Now that I have been discharged from the hospital, how do I get my medication refills?

Depending on the medication, your primary care physician may take over the management of your medications and be the one to call in any necessary refills. However, your doctor will want to see you in their office before assuming this responsibility.

How do I get a copy of my medical records?

Contact the hospital you were discharged from and ask to speak with the medical records department.

Where do I get information about community resources, support groups, handicap placards, and resources or providers specific to brain injury?

For resources available to brain injury survivors, you can contact the Brain Injury Alliance of Arizona at (602) 323-9165.

Should I apply for Social Security Disability?

Individuals are encouraged to get information from their neurologist or rehabilitation physician on applying for Social Security Disability. The application can be initiated over the phone by calling (602) 640-2200.

Do the charges associated with a day treatment program cover all my expenses?

No. You can expect to have outside, separate charges. For example, physician visits, psychiatric consultations, audiology evaluations, dietician consultations, and neuro-ophthamology assessments are billed by and paid to those sources independently. You and your family are responsible for understanding and researching the limits of your insurance coverage.

Resources

BRAIN INJURY ASSOCIATION OF AMERICA

www.biausa.org

Provides information on prevention, education, research and advocacy. Many helpful links.

BRAIN INJURY ALLIANCE OF ARIZONA

www.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

www.braintrauma.org

Information and resources for persons with brain injury.

BRAIN INJURY RESOURCE CENTER

www.headinjury.com

Clearing house founded and operated by brain injury activists since 1985. Provides resources and helpful information.

TRAUMATIC BRAIN INJURY SURVIVAL GUIDE

www.tbiguide.com

This is an on-line book about TBI, available free or for a small donation.

THE TBIRD

<http://tbi-sci.org/tbird>

A resource directory for TBI covering hundreds of issues and services. Available for free on-line and for a fee in print.

DR. DIANE

www.health-helper.com

Provides solutions and resources to help people and organizations to overcome life obstacles. Also available are useful links to other websites.

BRAIN MATTERS

www.tbimatters.org

Providing education and resources for individuals with TBI, their family, friends and professionals.

TRAUMATIC BRAIN INJURY MODEL SYSTEMS

www.tbims.org

This is a list of sites that are funded by NIDRR as TBI systems of care.

TRAUMATIC BRAIN INJURY

www.neuroskills.com

Resource and information on brain injury rehab. How-to manuals are available for purchase. There are some good articles that are available to download.

THE PERSPECTIVES NETWORK ON-LINE

www.tbi.org

An extensive list of resources and links, multiple languages for commons questions and answers.

THE INTERNATIONAL BRAIN INJURY ASSOCIATION

www.internationalbrain.org

Great links, provides international perspectives.

HEAD INJURY HOTLINE

www.headinjury.com

Information and resources. Join a discussion group.

NEUROPSYCHOLOGY CENTRAL

www.neuropsychologycentral.com

Comprehensive listing and links related to neuropsychology.

CITY OF PHOENIX ADAPTIVE RECREATION

<http://www.phoenix.gov/parks/adaptiverec/index.html>

CITY OF CHANDLER RECREATIONAL THERAPY PROGRAMS

<http://www.chandleraz.gov/default.aspx?pageid=187>

VIRGINIA G. PIPER SPORTS AND FITNESS CENTER

<http://www.sprofit.org/>

MOBILITY CENTER

<http://www.valleymetro.org/accessibility/mobilitycenter>

ARIZONA DISABLED SPORTS

<http://www.ArizonaDisabledSports.com>

THERAPEUTIC RECREATION DIRECTORY

<http://www.recreationtherapy.com/>

THERAPRO, INC.

<http://www.therapro.com/Default.aspx>

CAREPAGES

<http://www.carepages.com/>

CarePages is a free service that helps patients communicate with family and friends about their condition and health.

CARING BRIDGE

www.caringbridge.org

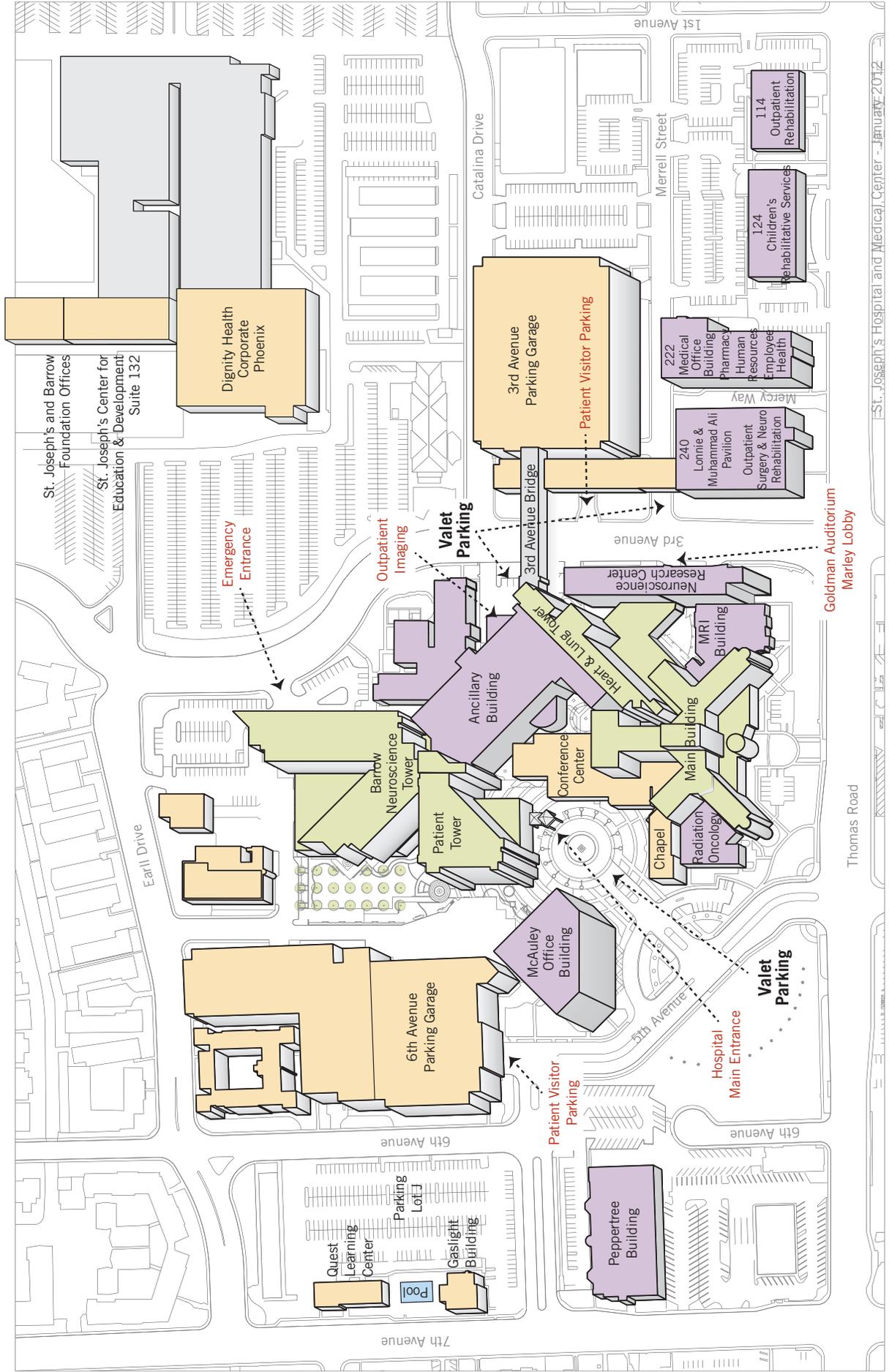
Caring Bridge is a free service that helps patients communicate with family and friends about their condition and health.

BRAINBALL

<http://www.Barrowbrainball.com/>

Barrow Brainball is an exciting arcade-style football runner game that teaches children how to safely avoid collisions with other players, providing valuable concussion education to young athletes.

Dignity Health Campus Map





Dignity Health.
St. Joseph's Hospital and
Medical Center