



Shepherd Center

# rebuilding, together

a guide for caregivers

*acquired brain injury rehabilitation / courtesy of shepherd center*

You will likely get a lot of information about brain injury in the coming days. Caregivers, well-meaning friends, the Internet, brain injury support groups, and families of other patients are all good sources of information, but it's a lot to take in. Don't try to learn everything at one time. Rely on your loved one's professional caregivers to let you know what you need to be concerned about next. *You've come to the right place, and your loved one is in the hands of experienced caregivers.*

## The first few hours, days and weeks following a brain injury are an uncertain and difficult time for a patient's loved ones. Getting over the shock of the initial injury and learning everything you need to know about what will come next can be overwhelming.

Because recovery from brain injury is unpredictable, it can be very frustrating. The medical world is sometimes fast-paced, and care happens around the clock. There is a whole new language to learn. Answers may seem hard to come by right now. Understanding all of this and what it means for your loved one will come in time. Right now, you need to do what you can to cope and to take care of yourself, hour by hour and then day by day.

In the pages of this booklet, you'll find information and advice that will help you through these first weeks. You'll also find comments from families of patients who have traveled this road before you.

***But more than anything else, they want you to know it's going to be OK.***

Whatever level of recovery your loved one makes, you are surrounded by a team of knowledgeable and caring professionals who will help you make the changes you'll need to make to return to a more normal daily routine.



### What you will find in this booklet:

- Brain Injury 10
- Recovery From Traumatic Brain Injury
- What To Expect In The Intensive Care Unit
- What You Can Do
- What To Expect In The Rehab Setting
- Keeping Track Of The Details
- Taking Care Of Yourself
- Resources

## *brain injury 101*

The most important — and sometimes frustrating — thing to know is that every person’s recovery from brain injury is different. We can make some assumptions based on the location, type and extent of injury, but in the end, each person’s recovery will be different. Brain injury can affect a person physically and emotionally, and can also affect a way a person thinks (cognition) and acts (behavior).

### SOME PROBLEMS WE WILL LOOK FOR INCLUDE:

#### PHYSICAL

- Moving certain body parts
- Bowel and bladder control
- Swallowing
- Speaking
- Balance and coordination
- Vision

#### EMOTIONAL

- Depression
- Anxiety
- Apathy
- Mood swings

#### COGNITIVE

- Disorientation (confusion)
- Attention
- Language
- Problems processing colors
- Memory
- Reasoning, problem solving, judgment
- Thought processing
- Poor insight

#### BEHAVIORAL

- Poor initiation
- Impulsivity
- Saying or doing inappropriate things
- Agitation
- Acting out

### UNDERSTANDING STROKE

- A stroke is an interruption of the blood supply to any part of the brain. Sometimes it’s called a “brain attack.” How a stroke patient is affected depends on where the stroke occurs in the brain and how much of the brain is damaged.
- Rehabilitation is an important part of recovering from a stroke. Through rehabilitation, you relearn or regain basic skills such as speaking, eating, dressing and walking. The goal is to improve function so that you become as independent as possible.

## recovery from traumatic brain injury

It is not uncommon for a person with a traumatic brain injury to be unconscious. Doctors use different scales to assess how awake and alert a person with a brain injury might be. The below scales are used with people who have had a traumatic brain injury to better understand their recovery process.

### GLASGOW COMA SCORE (GCS)

The Glasgow Coma Scale (GCS) is scored between 3 and 15. It is composed of three parameters: best eye response, best verbal response and best motor response.

#### Best Eye Response (4)

1. No eye opening
2. Eye opening to pain
3. Eye opening to verbal command
4. Eyes open spontaneously

#### Best Verbal Response (5)

1. No verbal response
2. Incomprehensible sounds
3. Inappropriate words
4. Confused
5. Orientated

#### Best Motor Response (6)

1. No motor response
2. Extension to pain
3. Flexion to pain
4. Withdrawal from pain
5. Localizing pain
6. Obeys commands

You should always look at a GCS broken down by components — not just the total. A Coma Score of 13 or higher correlates with a mild brain injury, 9 to 12 is a moderate injury, and 8 or less, a severe brain injury.

### THE RANCHO LOS AMIGOS SCALE

The Rancho Los Amigos scale was developed at the Rancho Los Amigos Hospital in California and is often used by doctors and therapists to explain the behavioral, cognitive and emotional changes that take place during healing.

**Level 1 — No Response:** Patient appears to be in a deep sleep and does not respond to voices, sounds, light or touch.

**Level 2 — Generalized Response:** Patient reacts inconsistently and non-purposefully to stimuli; first reaction may be to deep pain; may open eyes but will not seem to focus on anything in particular.

**Level 3 — Localized Response:** Patient responses are purposeful but inconsistent, and are directly related to the type of stimulus presented, such as turning head toward a sound or focusing on a presented object; may follow simple commands in an inconsistent and delayed manner.

**Level 4 — Confused, Agitated:** Patient is in a heightened state of activity; severely confused, disoriented and unaware of present events. Reacts to own inner confusion, fear or disorientation. Behavior is frequently bizarre and inappropriate to the immediate environment. Excitable behavior may be abusive or aggressive.

**Level 5 — Confused, Inappropriate, Non-Agitated:** Patient appears alert; responds to simple commands. Follows tasks for two to three minutes but easily distracted by environment; frustrated; verbally inappropriate; does not learn new information.

**Level 6 — Confused-Appropriate:** Patient follows simple directions consistently; needs cueing; can relearn old skills such as activities of daily living, but memory problems interfere with new learning; some awareness of self and others.

**Level 7 — Automatic-Appropriate:** If physically able, patient goes through daily routine automatically, but may have robot-like behavior and minimal confusion; shallow recall of activities; poor insight into condition; initiates tasks but needs structure; poor judgment, problem-solving and planning skills.

**Level 8 — Purposeful-Appropriate:** Patient is alert, oriented; recalls and integrates past and recent events; learns new activities and can continue without supervision; independent in home and living skills; capable of driving; deficits in stress tolerance, judgment; abstract reasoning persists; may function at reduced social level.

**Level 9 —** Patient independently shifts back and forth between tasks and completes them accurately for at least two consecutive hours; aware of and acknowledges impairments when they interfere with task completion; requires standby assistance to anticipate a problem before it occurs; depression may continue; patient may be easily irritable and have a low frustration tolerance.

**Level 10 —** Patient is able to handle multiple tasks simultaneously in all environments but may require periodic breaks. Irritability and low frustration tolerance may persist when feeling sick, fatigued and/or under emotional distress.

## *what to expect in the intensive care unit*

Your loved one will be in the Intensive Care Unit (ICU) of the hospital, where nurses and other caregivers can constantly monitor his or her condition. Your first view of your loved one might be a little scary.



- Don't be alarmed by the number of tubes and wires you see hooked up to your loved one's body. They all serve a purpose in delivering medication or monitoring the body functions so that we can be aware of even the slightest change.
- Your loved one may have had her head shaved in one area, and you may see stitches or a bandage. The hair will grow back.
- You may see swelling and bruising, depending on the nature of the injury; but this will heal.
- The patient may seem stiff and uncomfortable, or relaxed with heavy limbs. This depends on the nature of the injury, and the doctor will explain this to you.
- If your loved one has been moving around a lot in bed, the nurses may gently restrain his movement with cloth restraints. This may upset you, but remember that it's done to keep the patient safe and relatively still.
- Visiting hours in the ICU are limited. Nurses will tell you when you can visit.

## *what you can do*

Always check with your loved one's caregivers before initiating any activity, and use the following information to help you know what might be appropriate.

### WHEN YOUR LOVED ONE IS IN A COMA

Ranges from total non-responsiveness to minimally conscious.

- Don't overdo it. Allow time to rest between your visits.
- Limit the number of visitors at one time and maintain a calm tone of voice.
- Be aware that at this level, it is normal for a person to respond incorrectly, slowly or not at all.
- Sounds of familiar music, people, pictures, a favorite blanket or stuffed toy may be brought in.
- Talk in a normal tone of voice.
- Remind your loved one of the date, place and situation.
- Talk about familiar events.
- Assume he or she can hear you. Be careful not to say anything upsetting within earshot.
- Ask the person to do simple things, like "open your eyes" or "squeeze my hand and release it."

### WHEN YOUR LOVED ONE IS IN REHABILITATION

More responsive, but also confused and sometimes agitated.

- Provide a calm, quiet environment.
- Decrease extra noises from television or music.
- Talk in short, simple sentences.
- Orient the person to the day, place and situation.
- Don't argue with the person. Be aware that some confusion and agitation is expected.
- Don't take bad behavior personally. This confusion and agitation is expected.
- Give your loved one plenty of time to rest.



*“When the doctors told us it may take a while for our son to respond, I didn’t realize just how long ‘a while’ might be. But every step of the way, we have had the emotional and physical support we’ve needed to care for our son.”*

— Mother of a 23-year-old who was injured in a car accident

## *what to expect in the rehab setting*

As your loved one's health status improves, the doctor may recommend transferring into a rehabilitation program. Typically, the main goals of rehabilitation are to increase a person's strength, learn new ways to do things after an injury and help them return to their lives and community. Not only is this a time for your loved one to learn, but it's a time for you to learn how to help them.



### WHAT YOU SHOULD BRING TO REHABILITATION FOR YOUR LOVED ONE:

- Loose comfortable clothing such as:
  - elastic waist shorts
  - sweat pants
  - T-shirts
- Socks
- Underwear (consider boxers)
- Shoes (buy shoes at least one size larger and make sure they have a rubber sole)
- Toiletry items such as a
  - toothbrush
  - toothpaste
  - comb
  - brush
  - shampoo
  - soap
  - deodorant
- Familiar items such as
  - photos
- Comfort items, such as a favorite
  - pillow
  - blanket
  - music




## *keeping track of the details*

This journey is a long one, and there will be many detours along the way. Once the first few hours or days have passed, you must take breaks from the hospital to sustain yourself for the coming weeks and months. You also need to find a system that works for you in terms of how you organize the questions you have, the information you need to receive and the people with whom you talk.

**BEING A CAREGIVER IS NOT SOMETHING YOU MAY BE AUTOMATICALLY PREPARED TO DO, BUT THESE IDEAS WILL HELP:**

- **Buy several small notebooks.**  
Use one for phone numbers, one for doctor/treatment team information and questions, and one for information about insurance and other financial matters.
- **Choose a spokesperson.**  
Family members and friends will want information, and it is exhausting to repeat the daily updates. You can appoint someone to keep notes and provide updates via phone or the Internet to update concerned family and friends.
- **Use this time to learn about brain injury, but take it slow.**  
There is a lot of information, and it can be overwhelming. The library staff at the hospital, the chaplain and your loved one's case manager can help supplement the information you receive from the doctors.
- **Start a journal if it seems like something that would help you deal with your grief.**  
Reading it might be helpful to your loved one as he/she recovers.



“Talk to them, play the music they like and let younger children help, too. You never know what may trigger a response. Show them your love and your smiles, not your tears. Stay positive.”

— Mother of a 17-year-old who experienced an eight-week coma when the van he was riding in was broadsided by a drunk driver

## *taking care of yourself*

Taking care of yourself may seem time-consuming or even selfish, but your loved one needs you to be rested, well-fed, alert and energetic so you are up to the task of caregiving.

### HERE ARE SOME THINGS YOU SHOULD DO FOR YOURSELF:

- Save your energy by resting when you can.
- Eat healthy meals; skip the vending machines.
- Exercise a little each day; go for a walk and stretch your muscles.
- Leave the hospital for a little while. Your loved one is in good hands.
- If you are experiencing any medical problems, such as heart palpitations, muscle aches and pains, headaches or difficulty thinking, sleeping, remembering things or making decisions, call your doctor.
- Keep life as normal as possible for your children if you have them, and try to do something special with them once a week.
- Ask friends and family to write short notes instead of calling. That way you'll have something to read to your loved one.
- Talk about your feelings with family, friends or someone at the hospital (a psychologist, counselor, case manager, chaplain or other staff members can help you).
- Try to delegate to others and accept offers of help from family and friends; it gives them a way to be a part of the recovery. You might keep a list of things that need to be done (caring for pets and houseplants, picking up the mail, scheduling activities for children, etc.) so that you'll be prepared when someone asks.
- Allow yourself to put off "until tomorrow" what doesn't have to be done in one day, but do try to take care of some personal business every day.

*“The people on our street took care of the dog and brought food three days a week; it was absolutely wonderful. There was one person who coordinated the whole thing, and it grew to involve the whole neighborhood. It was such a relief that it is hard to put into words.”*

— Husband of a woman who experienced a two-week coma and a five-month hospital stay after a car accident

## resources

The Noble Learning Resource Center at Shepherd Center is a library with information especially for family members and friends of people with acquired brain injury. The knowledgeable staff can help you locate the right resources. The library also has computers with Internet access.

**Brain Injury Association of America**  
1776 Massachusetts Avenue, NW  
Suite 100  
Washington, DC 20036  
800-444-6443 or 202-296-6443  
[www.biausa.org](http://www.biausa.org)

**Head Injury Hotline**  
212 Pioneer Building  
Seattle, WA 98104  
206-621-8558  
[www.headinjury.com](http://www.headinjury.com)

**American Heart Association**  
7272 Greenville Avenue  
Dallas, TX 75231  
888-4-STROKE  
[www.americanheart.org](http://www.americanheart.org)

**National Brain Tumor Foundation**  
414 Thirteenth Street, Suite 700  
Oakland, CA 94612-2603  
800-934-CURE  
[www.braintumor.org](http://www.braintumor.org)

**American Brain Tumor Association**  
2720 River Road, Suite 146  
Des Plaines, IL 60018  
800-886-2282  
[www.abta.org](http://www.abta.org)

**The Family Caregiver Alliance**  
425 Bush Street, Suite 500  
San Francisco, CA 94108  
415-434-3388  
800-245-6686  
[www.caregiver.org](http://www.caregiver.org)

**Brain and Spinal Cord  
InjuryTrust Fund**  
2 Peachtree Street NW  
Suite 8-212  
Atlanta, GA 30303  
404-651-5112  
[www.bsitf.state.ga.us](http://www.bsitf.state.ga.us)

**Brain Injury Association  
of Georgia**  
1441 Clifton Road  
Atlanta, GA 30322  
404-712-5504  
[www.braininjurygeorgia.org](http://www.braininjurygeorgia.org)

**Brain Injury Peer Visitor Association**  
355 Guildhall Grove  
Alpharetta, GA 30022  
770-330-8416  
[www.braininjurypeervisitor.org](http://www.braininjurypeervisitor.org)



Visit us online at [shepherd.org](http://shepherd.org)

The Billi Marcus Building

The Jane Woodruff Pavilion

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