

Resources Offered by the MSKTC  
to Support Individuals Living with

# Traumatic Brain Injury

Edition 1  
November 2013



[www.MSKTC.org/TBI](http://www.MSKTC.org/TBI)

## Traumatic Brain Injury

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**Edition 1**  
**November 2013**

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**Facebook: Traumatic Brain Injury Model Systems**



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## About the Model Systems Knowledge Translation Center

The Model Systems Knowledge Translation Center (MSKTC) summarizes research, identifies health information needs, and develops information resources to support the Model Systems programs in meeting the needs of individuals with spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury (Burn). The health information offered through the MSKTC is not meant to replace the advice from a medical professional. Users should consult their health care provider regarding specific medical concerns or treatment.

The current MSKTC cycle is operated by American Institutes for Research® (AIR®) in collaboration with the Center for Chronic Illness and Disability at George Mason University and BrainLine at WETA. The Center is funded by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) under grant number H133A110004.

<http://www.msktc.org>

## About the Model Systems Program

Model Systems are specialized programs of care in spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury (Burn). Model Systems conduct innovative and high-quality research, provide patient care, and offer other services to improve the health and overall quality of life for individuals with SCI, TBI, and burn injury. Model Systems are funded by the National Institute on Disability and Rehabilitation Research (NIDRR).

### Traumatic Brain Injury Model Systems

#### *2012–2017 Funding Cycle*

#### **Mayo Clinic Traumatic Brain Injury Model System**

Mayo Clinic, Rochester, MN

#### **The Moss Traumatic Brain Injury Model System**

Albert Einstein Healthcare Network, Philadelphia, PA

#### **New York Traumatic Brain Injury Model System**

Mount Sinai School of Medicine, New York, NY

#### **North Texas Traumatic Brain Injury Model System**

The University of Texas, Southwestern Medical Center, Dallas, TX

#### **Northern New Jersey Traumatic Brain Injury System**

Kessler Institute for Rehabilitation, West Orange, NJ

#### **Ohio Regional Traumatic Brain Injury Model System**

Ohio Valley Center for Brain Injury Prevention and Rehabilitation, Columbus, OH

#### **South Florida Traumatic Brain Injury Model System**

University of Miami, Miller School of Medicine, Miami, FL

#### **Rehabilitation Hospital of Indiana Traumatic Brain Injury Model System**

Indiana University School of Medicine, Indianapolis, IN

#### **The Rocky Mountain Regional Brain Injury System**

Craig Hospital, Englewood, CO

#### **Rusk Rehabilitation Traumatic Brain Injury Model System**

Rusk Institute of Rehabilitation Medicine, New York, NY

#### **Spaulding-Harvard Traumatic Brain Injury Model System**

Spaulding Rehabilitation Hospital, Boston, MA

#### **The Texas TBI Model System of TIRR**

TIRR Memorial Hermann, Houston, TX

#### **UAB Traumatic Brain Injury Model System**

University of Alabama at Birmingham, Birmingham, AL

#### **University of Pittsburgh Traumatic Brain Injury Model System**

University of Pittsburgh School of Medicine, Pittsburgh, PA

#### **University of Washington Traumatic Brain Injury Model System**

University of Washington, Seattle, WA

#### **Virginia Commonwealth Traumatic Brain Injury Model System**

Virginia Commonwealth University, Richmond, VA

## About the Traumatic Brain Injury National Data and Statistical Center

The Traumatic Brain Injury Model Systems National Data and Statistical Center (TBINDSC) advances medical rehabilitation by increasing the rigor and efficiency of scientific efforts to longitudinally assess the experience of individuals with traumatic brain injury (TBI). The TBINDSC provides technical assistance, training, and methodological consultation to 16 TBIMS centers as they collect and analyze longitudinal data from people with TBI in their communities, and they conduct research toward evidence-based TBI rehabilitation interventions.

The TBINDSC is operated by Craig Hospital Research Department and is funded by the National Institute on Disability and Rehabilitation Research.

**<https://www.tbindsc.org/>**

## Contents

Overview of Traumatic Brain Injury Products Offered Through the MSKTC .....	4
Listing of Traumatic Brain Injury Products Offered Through the MSKTC.....	5
Opportunities To Participate in MSKTC Activities .....	6
Collection of Traumatic Brain Injury Factsheets Offered by the MSKTC .....	6
Traumatic Brain Injury and Acute Inpatient Rehabilitation .....	9
Alcohol Use After Traumatic Brain Injury.....	13
Balance Problems After Traumatic Brain Injury .....	17
Cognitive Problems After Traumatic Brain Injury .....	20
Couples' Relationships After Traumatic Brain Injury .....	24
Depression After Traumatic Brain Injury.....	28
Driving After Traumatic Brain Injury .....	31
Emotional Problems After Traumatic Brain Injury .....	34
Fatigue and Traumatic Brain Injury .....	38
Headaches After Traumatic Brain Injury .....	40
Returning to School After Traumatic Brain Injury .....	43
Seizures After Traumatic Brain Injury .....	47
Sexuality After Traumatic Brain Injury .....	50
Sleep and Traumatic Brain Injury.....	53
Understanding TBI—Part 1: What happens to the brain during injury and in the early stages of recovery from TBI? .....	57
Understanding TBI—Part 2: Brain injury impact on individuals' functioning .....	61
Understanding TBI—Part 3: The Recovery Process .....	65
Understanding TBI—Part 4: The impact of a recent TBI on family members and what they can do to help with recovery .....	68
Facts About the Vegetative and Minimally Conscious States After Severe Brain Injury .....	72

## Overview of Traumatic Brain Injury Products Offered Through the MSKTC

The Model Systems Knowledge Translation Center (MSKTC) offers a variety of free resources on traumatic brain injury (TBI) to support people with disabilities and their caregivers, researchers, practitioners and clinicians, and policy makers. The following resources are available at [www.MSKTC.org/TBI](http://www.MSKTC.org/TBI).

### TBI Factsheets

The MSKTC collaborates with TBI Model Systems to produce evidence-based and consumer-friendly factsheets.

### TBI Slideshows

The MSKTC develops traditional and narrated slideshows based on information from select factsheets. These resources are developed for users who prefer a format with more images, less text, or an audio option.

### TBI Hot Topic Module

The MSKTC developed a Hot Topic Module, which is a collection of resources such as videos, factsheets, and slideshows to support individuals who live with TBI.

### TBI Quick-Turnaround Reviews

The MSKTC provides quick reviews of Model Systems research studies funded by the National Institute on Disability and Rehabilitation Research (NIDRR). Those reviews offer timely summaries of newly released Model System research studies using lay language for easy access.

### TBI Systematic Reviews

The MSKTC collaborates with Model System programs to conduct systematic reviews on high-priority health topics to inform clinical practice. Results of a systematic review provide the best information for making decisions about treatment, practice, or behavior.

### TBI Database

The MSKTC maintains a database of nearly 600 TBI citations and abstracts of studies funded by NIDRR.

## Listing of Traumatic Brain Injury Products Offered Through the MSKTC

### TBI Products Available on MSKTC.org/TBI as of November 2013

#### TBI Factsheets

- Understanding Traumatic Brain Injury (4 Part Series)
- Traumatic Brain Injury and Acute Inpatient Rehabilitation
- Alcohol Use After Traumatic Brain Injury
- Balance Problems After Traumatic Brain Injury
- Cognitive Problems After Traumatic Brain Injury
- Depression After Traumatic Brain Injury
- Driving After Traumatic Brain Injury
- Emotional Problems After Traumatic Brain Injury
- Fatigue and Traumatic Brain Injury
- Headaches After Traumatic Brain Injury
- Returning to School After Traumatic Brain Injury
- Seizures After Traumatic Brain Injury
- Sexuality After Traumatic Brain Injury
- Sleep and Traumatic Brain Injury
- Facts About the Vegetative and Minimally Conscious States After Severe Brain Injury

#### TBI Database

- 560 studies conducted by TBI Model Systems researchers

#### TBI Slideshows

- Sexuality After Traumatic Brain Injury
- Couples' Relationships After Traumatic Brain Injury

#### TBI Hot Topic Module

- Relationships After TBI

#### TBI Systematic Reviews

- TBI & Depression Interventions
- TBI & Equity with Substance Abuse Brief Interventions
- TBI & Headache Interventions

#### TBI Quick-Turnaround Reviews

- The Community Integration Questionnaire
- Application and Clinical Utility of the Glasgow Coma Scale

### Coming Soon to MSKTC.org/TBI

#### TBI Factsheets

- TBI & Vocational Rehabilitation
- TBI & Vision Problems

#### TBI Systematic Reviews

- TBI & Effectiveness of Comprehensive vs. Targeted Neurobehavioral Strategies
- TBI & Anxiety Measures
- Driving after TBI

## Opportunities To Participate in MSKTC Activities

Involvement from the field plays a critical role in the success of the MSKTC. Periodically, we recruit individuals with traumatic brain injury and their family members, caregivers, and clinicians to participate in MSKTC activities. We sometimes offer a small financial token of appreciation to participants. Examples of activities include:

- ◆ Providing feedback on factsheets
- ◆ Offering input on videos
- ◆ Participating in a conversation about the needs of caregivers

If you are interested in learning more about these activities or participating, please email [MSKTC@air.org](mailto:MSKTC@air.org) or call 202-403-5600.

## Collection of Traumatic Brain Injury Factsheets Offered by the MSKTC

This section contains TBI factsheets offered by the MSKTC as of October 2013. These and other resources are available at no charge on [www.MSKTC.org/TBI](http://www.MSKTC.org/TBI).

- ◆ Alcohol Use After Traumatic Brain Injury
- ◆ Balance Problems after Traumatic Brain Injury
- ◆ Cognitive Problems after Traumatic Brain Injury
- ◆ Couples' Relationships After Traumatic Brain Injury
- ◆ Depression After Traumatic Brain Injury
- ◆ Driving After Traumatic Brain Injury
- ◆ Emotional Problems After Traumatic Brain Injury
- ◆ Facts about the Vegetative and Minimally Conscious States after Severe Brain Injury
- ◆ Fatigue and Traumatic Brain Injury
- ◆ Headaches After Traumatic Brain Injury
- ◆ Returning to School After Traumatic Brain Injury
- ◆ Seizures and Traumatic Brain Injury
- ◆ Sexuality After Traumatic Brain Injury
- ◆ Sleep and Traumatic Brain Injury
- ◆ Traumatic Brain Injury and Acute Inpatient Rehabilitation
- ◆ Understanding Traumatic Brain Injury (4 Part Series)



# Traumatic Brain Injury and Acute Inpatient Rehabilitation

## What is inpatient rehabilitation?

Inpatient rehabilitation is designed to help you improve function after a moderate to severe traumatic brain injury (TBI) and is usually provided by a team of people including physicians, nurses and other specialized therapists and medical professionals.

## What are the common problems addressed by inpatient rehabilitation?

- Thinking problems – difficulty with memory, language, concentration, judgment and problem solving.
- Physical problems – loss of strength, coordination, movement and swallowing.
- Sensory problems – changes in sense of smell, vision, hearing and tactile touch.
- Emotional problems – mood changes, impulsiveness and irritability.

## Am I eligible to receive inpatient rehabilitation?

You will receive inpatient rehabilitation if:

- You have a new TBI that prevents you from returning home to family care.
- Your medical condition is stable enough to allow participation in therapies. For people relying on Medicare for funding, this means being able to participate in at least 3 hours of therapy per day. (Specialized rehabilitation in a nursing facility is an option for those who cannot participate in 3 hours of rehabilitation per day.)
- You are able to make progress in therapies.
- You have a social support system that will allow you to return home or to another community care setting after reasonable improvement of function.
- You have insurance or other ways to cover the cost of treatment.

## How does inpatient rehabilitation work?

Your therapies will be designed to address your specific needs. You will receive at least 3 hours of different types of therapy throughout the day with breaks in between, 5-7 days a week.

You will be under the care of a physician who will see you at least 3 times a week.

Most TBI rehabilitation inpatients participate in:

- Physical therapy
- Occupational therapy
- Speech therapy

Each of these therapies may be provided in an individual or group format.

## Rehabilitation team

Rehabilitation care usually involves a team of highly trained practitioners, called your “multidisciplinary team.” This team works together every day and shares information about your treatment and recovery. Once a week all the team members meet formally to discuss your progress and discharge plan in a team conference.

Members of your multidisciplinary team are:

**Physician:** This may be a physiatrist (physician whose specialty is rehabilitation medicine), neurologist or other specialist familiar with TBI rehabilitation. He/she is in charge of your overall treatment and directs your rehabilitation program. The physician will:

- Evaluate your physical abilities, along with your thinking and behavior.
- Prescribe medication as necessary to manage mood, sleep, pain and nutrition.
- Prescribe tailored therapy orders for physical therapy, occupational therapy and speech therapy.

**Rehabilitation Nurse:** The rehabilitation nurse works very closely with the physician in managing medical problems and preventing complications. The nurse will:

- Assess a variety of issues, including self-care, bowel and bladder function, sexuality, nutrition and mobility.
- Reinforce the treatments of the other team members.
- Provide you and your family with education about your brain injury and medications.

**Psychologist/Neuropsychologist:** He/she will assess and treat problems you may have with thinking, memory, mood and behavior. The psychologist/neuropsychologist may also provide counseling and education to your family members, thus ensuring that they have an understanding of the treatment plan and possible outcomes.

**Physical therapist:** The physical therapist (PT) will help you improve your physical function and mobility. The PT’s role is to teach you how to be as physically independent and as safe as possible within your environment. This is accomplished through therapeutic exercises and re-education of your muscles and nerves, with the goal of restoring normal function. Specific goals to be accomplished in the physical therapy gym include strengthening your muscles and improving endurance, walking and balance.

**Occupational therapist:** Occupational therapists (OT) provide training in activities of daily living to help you become more independent. These activities typically include eating, bathing, grooming, dressing, and transferring to and from your bed, wheelchair, toilet, tub and shower. The OT will work with you on underlying skills, such as strength, balance and trunk control. Depending on the center, occupational therapists may also:

- Assess your thinking skills, such as orientation, memory, attention, concentration, calculation, problem-solving, reasoning and judgment.
- Assess your visual problems.
- Help you manage more complex activities such as meal preparation/cooking, money management, and getting involved in community activities.
- Recommend and order appropriate equipment you may need before returning home.

**Speech-language pathology therapist:** The speech-language pathology therapist is responsible for the treatment of speech, swallow and communication problems. She/he will:

- Help you with communication problems such as difficulty understanding what others say or expressing yourself clearly.

- Teach you exercises and techniques to improve your ability to speak and express yourself, including exercises to strengthen the muscles used in speech/swallowing, and speech drills to improve clarity.
- Assess your language skills, such as orientation, memory, attention, concentration, calculation, problem-solving, reasoning and judgment.
- Provide a communication device if you have a breathing tube (tracheostomy).
- Evaluate your swallowing abilities if you have difficulty swallowing (dysphagia).
- If needed, make recommendations about the types and consistencies of foods and drinks that you can safely consume.

**Recreation therapist:** The role of the recreation therapist is to provide recreational resources and opportunities in order to improve your health and well-being and get you reconnected in the community. Returning to recreation and/or finding new recreational activities is an important part of recovery. This may include outings or in-hospital social and group activities.

**Social worker:** The social worker will provide you and your family with information about community resources and help plan for your hospital discharge and return to the community. She/he will:

- Help determine your eligibility for benefits, such as Medicaid and Social Security.
- Make referral to community resources for you and your family.
- Provide ongoing supportive counseling to help you adjust to your new situation.

**Nutritionist/Dietitian:** The dietitian evaluates your nutritional status and makes recommendations about proper nutrition and diet. Patients are frequently malnourished and underweight after a hospital stay. Individualized attention to diet and caloric intake assists in recovery. The dietitian will also educate you regarding menu selection, proper food consistencies, diet changes, etc., as it fits your needs.

## How can your family members offer support during inpatient rehabilitation?

Family members can:

- Get to know the team members caring for you.
- Ask when and how they can participate in therapy sessions.
- Ask about improvements that they can expect to see during rehabilitation.
- Ask questions about the rehabilitation therapies.
- Ask about and discuss the discharge process early on in your stay, since the time in inpatient rehabilitation can be short.

## What happens after inpatient rehabilitation?

Leaving inpatient rehabilitation can be an anxiety-producing transition. Many questions can arise at the time of discharge, such as:

- How will I be able to continue to progress after I leave the hospital?
- Who will take care of me when I go home?
- What if I need more help than my family can provide for me?

To ease this transition, social workers make sure that you have what you need to safely continue recovery after you leave the hospital.

As the date of your discharge approaches, depending on your particular setting, the social worker, care manager, and/or discharge planner will meet more regularly with you and your family to form a discharge plan. They can:

- Provide emotional support.
- Help you get the care you need. This includes where you will get the services you need, who will provide them, and maximizing use of insurance benefits.

- Identify community resources (e.g., finances, home care, transportation, and community service organizations) that can help you function well in your community. This often includes government services such as SSI (Supplemental Security Income), SSDI (Social Security Disability Insurance), Medicaid, Medicare, and other disability benefits.

## Discharge Plans

Every discharge plan is different and reflects a patient's unique personal and social situation. Recovery from a brain injury takes months and even years, so after discharge most people will require ongoing therapy. Discharge plans fall roughly into one of four categories:

- **Discharge Home, with Referral for Home-Based Rehabilitation Services:** This discharge plan is appropriate for those people who are well enough to be at home, but who are not well enough to travel for therapy. In these cases, the social worker will make a referral to a nursing agency that will visit you at home, assess your needs, and provide needed services, which may include physical and occupational therapy and a home health attendant. However, family is almost always needed to provide some of the help that you will need at home.
- **Discharge Home, with Referral for Outpatient Services:** This discharge plan is appropriate for those people who are well enough to be at home and able to travel to an outpatient clinic for therapy. In this case, family members will provide all the help and supervision you need at home, and your rehabilitation therapies will be provided through an outpatient clinic that is convenient to you.
- **Discharge to a Residential Brain Injury Rehabilitation Program:** This discharge plan is appropriate for people who are well enough to live in the community but require a supervised and structured environment. This option is generally best for persons who do not need inpatient supervision by a nurse or physician but may benefit from continued therapy

to transition back into the community. The availability of these programs varies based on insurance type and where you live.

- **Discharge to a Nursing Facility:** This discharge plan is appropriate for people who are not yet ready to return home and who would benefit from continuing their rehabilitation therapies in a structured environment with nursing care. The nursing facility can provide nursing care and ongoing rehabilitation therapy in specialized rehabilitation wings (sometimes called subacute rehabilitation), usually for up to three months. Length of stay varies based on medical need, degree of progress in that setting, and availability of rehabilitation benefit. If your team recommends a nursing facility that provides subacute rehabilitation, the social worker will help you find one that meets your individual needs.

## Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

## Source

Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the TBI Model System directors.

## Authorship

The TBI and Inpatient Rehabilitation factsheet was developed by Brian D. Greenwald, MD, in collaboration with the University of Washington Model Systems Knowledge Translation Center.

# Alcohol Use After Traumatic Brain Injury

## Introduction

Alcohol use and TBI are closely related. Up to two-thirds of people with TBI have a history of alcohol abuse or risky drinking. Between 30-50% of people with TBI were injured while they were drunk and about one-third were under the influence of other drugs. Around half of those who have a TBI cut down on their drinking or stop altogether after injury, but some people with TBI continue to drink heavily, which increases their risk of having negative outcomes.

After TBI, many people notice their brains are more sensitive to alcohol. Drinking increases your chances of getting injured again, makes cognitive (thinking) problems worse, and increases your chances of having emotional problems such as depression. In addition, drinking can reduce brain injury recovery. For these reasons, staying away from alcohol is strongly recommended to avoid further injury to the brain and to promote as much healing as possible.

## Facts about TBI and alcohol

### Alcohol and brain injury recovery

- Recovery from brain injury continues for much longer than we used to think possible. Many people notice improvements for many years after injury.
- Alcohol slows down or stops brain injury recovery.
- Not drinking is one way to give the brain the best chance to heal.
- People's lives often continue to improve many years after brain injury. Not drinking will increase the chance of improvement.

### Alcohol, brain injury and seizures

- Traumatic brain injury puts survivors at risk for developing seizures (epilepsy).
- Alcohol lowers the seizure threshold and may trigger seizures.
- Not drinking can reduce the risk of developing seizures.

### Alcohol and the risk of having another brain injury

- After a brain injury, survivors are at higher risk (3 to 8 times higher) of having another brain injury.

- Drinking alcohol puts survivors at an even higher risk of having a second brain injury. This may be because both brain injury and alcohol can affect coordination and balance.
- Not drinking can reduce the risk of having another brain injury.

## Alcohol and mental functioning

- Alcohol and brain injury have similar negative effects on mental abilities like memory and thinking flexibility.
- Alcohol magnifies some of the cognitive problems caused by brain injury.
- Alcohol may affect brain injury survivors more than it did before their injury.
- The negative mental effects of alcohol can last from days to weeks after drinking stops.
- Not drinking is one way to keep your mental abilities at their best and stay sharp and focused.

## Alcohol and mood

- Depression is about 8 times more common in the first year after TBI than in the general population.
- Alcohol is a “depressant” drug, and using alcohol can cause or worsen depression.
- Alcohol can reduce the effectiveness of anti-depressant medications. People who are taking antidepressants should not drink alcohol.
- One way to improve problems with sadness or depression after TBI is to stop or cut down on the use of alcohol.

## Alcohol and sexuality

- Lowered desire is the most common effect of TBI on sexuality.
- Alcohol reduces testosterone production in males.
- Alcohol reduces sexual performance (erection and ejaculation) in men.
- Alcohol reduces sexual satisfaction in men and women.

- Avoiding alcohol improves sexual ability and activity in men and women.

## How much alcohol is “safe” after TBI?

After TBI the brain is more sensitive to alcohol. This means that even one or two drinks may not be safe, especially when you need to do things that require balance, coordination and quick reactions, such as walking on uneven surfaces, riding a bicycle or driving a car. The fact is, there is no safe level of alcohol use after TBI.

## Alcohol and medications

Alcohol is especially dangerous after TBI if you are taking certain prescription medications. Alcohol can make some medicines less effective and can greatly increase the effects of others, potentially leading to overdose and death. Using alcohol along with anti-anxiety medications or pain medications can be highly dangerous because of the possible multiplying effect.

## What about using other drugs?

Alcohol is a drug. Almost everything mentioned above about alcohol applies equally to other drugs. If your drug of choice is something other than alcohol—such as marijuana, cocaine, methamphetamine or prescription drugs, anti-anxiety medications (benzodiazepines such as Ativan, Valium, or Xanax), or pain medication (opioids like Percocet, Oxycodone or Oxycontin)—many of the same principles apply. In addition, use of illegal drugs or misuse of prescription drugs can lead to legal problems.

If you use multiple drugs like alcohol and marijuana, or alcohol and pain pills, there is a higher risk of addiction and overdose. Using alcohol and pain medications together, or alcohol and anti-anxiety medications, has killed many people. Contact your doctor if you are drinking and using prescription drugs.

## What should you do?

The stakes are higher when people choose to use alcohol after having a TBI. Some people



continue drinking after a TBI and don't have any desire to change that behavior. Others know they probably should stop or reduce alcohol use, but don't know how or have tried in the past and not been successful.

There are many ways to stop using alcohol or other drugs and many ways to reduce the potential for harm. The great majority of people who have stopped having alcohol problems did it on their own. They got no professional help or counseling and did not use Alcoholics Anonymous (AA). Don't underestimate your ability to change if you want to.

## There are many ways to change, cut down or stop drinking

The key ingredients to changing your drinking are: (1) find people who will support your efforts to change your drinking; (2) set a specific goal; (3) make clear how you will meet your goal; (4) identify situations or emotions that can trigger drinking, and figure out ways to cope with those triggers ahead of time; and (5) find ways to reward yourself for sticking to your plan and meeting your goals.

If you have questions or concerns about your drinking, there are many ways to get information or help:

- Take a confidential on-line drinking assessment: <http://www.alcoholscreening.org/>.
- Talk to your physician about your concerns, and ask about medications that can help you resist relapse or reduce cravings for alcohol, such as naltrexone (Revia).
- Psychologists or other counselors in your brain injury rehabilitation program can help you get started on a treatment program that is right for you.
- Alcoholics Anonymous (AA) has helped millions of people. There are meetings in most towns and cities (<http://www.aa.org/>).
- Moderation Management (<http://www.moderation.org/>) and Smart Recovery (<http://www.smartrecovery.org/>) are alternatives to AA that do not use the 12-step model.

- Substance Abuse and Mental Health Services Administration (SAMHSA) is a federal program that can help you find a treatment facility wherever you live (<http://findtreatment.samhsa.gov/>; 800-662-4357).
- Private treatment: look in the Yellow Pages under substance abuse, chemical dependency counselor, or addiction treatment.

## Reduce the harm from drinking

For those who don't want to stop drinking, it is still possible to reduce some harm from drinking:

- Eat food and drink water before you drink alcohol. This will help reduce the sharp spike in blood alcohol level that can cause nausea, vomiting, falls, blackouts and alcohol poisoning.
- Plan your transportation so you don't drink and drive: have a non-drinking designated driver; plan to spend the night where you are doing your drinking; or drink only at home.
- To avoid dangerous peaks in blood alcohol concentrations, drink beer rather than hard liquor, or mix hard liquor with water instead of with sweet, carbonated beverages.
- Sip your drinks slowly (no more than one per hour). Drinking too fast can make the pleasant feelings of alcohol go away.
- Drinking in bars slows some people down because of the expense. However, be sure you do not drive after drinking.
- Take vitamins B1 (thiamine), B12 and folate to reduce the chances of alcohol-related brain damage.
- Keep your drinking to no more than two drinks per day. Or cut back on certain days of the week, such as weeknights.
- Take a drinking "holiday" (days or weeks when you decide not to drink at all). This can remind you of some of the benefits of being sober.

## How family members can help

No one can force another person to stop using alcohol or drugs, but you can have an influence. Attending Al Anon meetings can be a good

source of support for a friend or family member of someone who abuses alcohol or drugs, and it can help promote change. Planning an “intervention” where family and friends confront the person may help.

A program called Community Reinforcement and Family Training (CRAFT) has been found to work best. CRAFT takes a more positive, motivational approach that helps loved ones make not drinking more rewarding for the person with the alcohol problem. Research has shown that alcoholics are more likely to go into treatment if their loved ones follow the CRAFT method. To learn about CRAFT, see the book *Get Your Loved One Sober* in the Resources section below, or find a counselor familiar with this approach.

## Reference

Bombardier, C.H. & Turner, A. (2009). Alcohol and traumatic disability. In R. Frank & T. Elliott (Eds.), *The Handbook of Rehabilitation Psychology*, Second Edition (pp. 241–258). Washington, DC: American Psychological Association Press.

## Resources

- Brown, J., Corrigan, J., & Hammer, P. (2010). “Substance Abuse and TBI.” Brainline Webcast #4, Defense and Veterans Brain Injury Center. ([http://www.brainline.org/webcasts/4-TBI\\_and\\_Substance\\_Abuse/index.html](http://www.brainline.org/webcasts/4-TBI_and_Substance_Abuse/index.html))
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- Meyers, R.J., & Wolfe, B.L. (2004). *Get Your Loved One Sober: Alternatives to Nagging, Pleading, and Threatening*. Center City, MN: Hazelden Publications.
- Substance Abuse Resources and Disability Issues (SARDI); <http://www.med.wright.edu/citar/sardi/index.html>.

## Source

Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the TBI Model System directors.

## Authorship

*Alcohol Use After Traumatic Brain Injury* was developed by Charles Bombardier, PhD, in collaboration with the University of Washington Model Systems Knowledge Translation Center.

## Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.



# Balance Problems after Traumatic Brain Injury

People with traumatic brain injury (TBI) commonly report problems with balance. Between 30% and 65% of people with TBI suffer from dizziness and disequilibrium (lack of balance while sitting or standing) at some point in their recovery. Dizziness includes symptoms such as lightheadedness, vertigo (the sensation that you or your surroundings are moving), and imbalance.

How bad your balance problem is depends on many factors:

- How serious your brain injury is.
- Where in your brain you were injured.
- Other injuries you had along with your brain injury. For example, in a motor vehicle crash, you could suffer a TBI, cervical spine injury, and rib and leg fractures. All of these injuries will affect your ability to maintain your balance.
- Some medications used to manage the medical issues connected with the traumatic event or accident.

## What is “balance”?

Balance is the ability to keep your body centered over your feet. The ability to maintain your balance is determined by many factors, including your physical strength and coordination, your senses, and your cognitive (thinking) ability.

Most people can control their body movement within certain limits before losing their balance and needing to adjust their posture or take a step to keep from falling. Adjusting your posture or taking a step to maintain your balance before, during, and after movement is a complex process that is often affected after brain injury.

## Why is balance important?

When you have poor balance you have a high risk of falling and having another brain injury or broken bone. Maintaining balance while sitting and standing is important for all of our daily activities, including self care and walking. Poor balance can keep you from taking part in many types of activities, such as sports, driving, and work.

## Diagnosing balance problems

Many different kinds of health care providers may be involved in diagnosing and treating balance problems, including physiatrists (physical medicine or rehabilitation doctor), neurologists, otolaryngologists (ENT), and neuro-ophthalmologists. The first place to start is by having your physician review your medications, since this is a common cause of balance problems. Physical and occupational therapists may also help identify and treat balance problems.

Two commonly used tests for identifying balance problems are the Berg Balance Scale and the Dynamic Gait Index. Both of these tests can be used to track your progress as your balance improves with therapy and to provide information about potential risk of falls.

## What are common causes of balance problems after traumatic brain injury?

**Medications:** A number of commonly used medications can cause dizziness, lightheadedness and decreased balance. These include some blood pressure medications, antibiotics, tranquilizers, heart medications, and anti-seizure medications. Ask your doctor if any of the medications you are taking may be causing dizziness or balance problems. A change in medications or dosages may improve the problem.

A drop in blood pressure when standing or sitting up suddenly (called **postural hypotension**) can make you feel lightheaded and dizzy. It may occur when you get up quickly from sitting on the toilet or a chair, or getting out of bed. Having your blood pressure taken while in a lying, sitting and standing position may also help diagnose blood pressure-related balance problems.

**Problems with eyesight (vision impairments):** Eyesight is one of the key senses you need to keep your balance. Eyesight problems such as double vision, visual instability, partial loss of vision, and problems with depth perception can make your balance worse.

**Inner ear problems (vestibular impairments):** Your inner ear contains many tiny organs that help you keep your balance (called the vestibular system/labyrinth). Your inner ear has three loop-shaped structures (semicircular canals) that contain fluid and have fine, hair-like sensors that monitor the rotation of your head. It also has other structures (otolith organs) that monitor linear movements of your head. These otolith organs contain crystals that make you sensitive to movement and gravity. If your vestibular system is damaged from a head injury, you may have problems with balance, dizziness, or a sudden sensation that you're spinning. Three types of vestibular impairments are:

- **Benign paroxysmal positional vertigo (BPPV)** is one of the most common causes of vertigo. With trauma, the crystals in the inner ear can be moved out of place, making you sensitive to changes in gravity. BPPV is characterized by brief episodes of mild to intense vertigo. Symptoms are triggered by specific changes in head position, such as tipping your head up or down, and by lying down, turning over or sitting up in bed. You may also feel out of balance when standing or walking.
- **Labyrinthine concussion or injury** to the nerve to the vestibular system are also causes of vertigo and imbalance after brain injury.
- **Traumatic endolymphatic hydrops** occurs when there is a disruption of the fluid balance within the inner ear. When this happens, you may have periods of vertigo, imbalance and ringing in your ears that last for hours to days.

Problems with your ability to sense things (**sensory impairments**): For example, nerves in your feet send messages to your brain that help you keep your balance. If these nerves are damaged from your brain injury, your brain may not get the messages it needs. The brain may need to rely more on your eyesight and inner ear to keep your balance.

**Brainstem injury:** A traumatic injury to the brainstem and cerebellum (parts of the brain that control movement) can make it hard for you to walk and maintain your balance.

Leakage of inner ear fluid into the middle ear (called **perilymph fistula**) sometimes occurs after head injury. It can cause dizziness, nausea, and unsteadiness when walking or standing. It can get worse when you are more active and may get better with rest.

**Mental health issues:** Sometimes people with brain injuries have anxiety, depression or a fear of falling. These conditions can cause or increase balance problems. Doctors call this psychogenic dizziness.

## Treatment options

Balance problems can have many different causes, each one requiring a different treatment. Your doctor, physical and occupational therapists and/

or other health care providers will work with you to understand and treat all the different causes.

## Ways you can improve your balance:

Increasing your strength and flexibility will help your balance. Specific exercises include stretches for your ankle and hip muscles or strengthening activities for your legs, such as mini-squats, toe-raisers, or standing leg lifts. Go to [www.nia.nih.gov/Go4Life](http://www.nia.nih.gov/Go4Life) for more information about these exercises, or talk to your doctor or physical therapist.

Find your limits in balance by moving your body over your feet as far as you can without lifting your feet. This will help you develop balance strategies to prevent losing your balance. You can also practice movements that allow you to transition from one position to another, such as going from sitting to standing, reaching above your head to get something off a shelf, or picking up something off the ground.

Practice standing or walking in different conditions. For example, you can practice standing with your eyes closed to decrease your dependency on vision for balance or stand on a pillow to improve your ability to use vision for balance. Change how far apart your feet are and work on balance by bringing them closer together, in front of one another or even stand on one leg.

Practice activities that will improve your balance while walking, such as walking longer distances; walking and keeping up with someone else while carrying on a conversation; walking over different surfaces, such as on grass and sidewalks; and walking in crowded places such as the grocery store.

Be cautious when working on your balance, and make sure you work at an appropriate level to avoid falling when no one is around. A physical or occupational therapist can help design a program that is safe for you to practice at home.

BPPV is treated by using movements to relocate the crystals in your inner ear back to where they belong. To learn more about the treatment of BPPV go to <http://www.tchain.com/otoneurology/disorders/bppv/bppv.html>.

## How quickly can your balance improve?

How quickly your balance problems improve depends on the extent of injury and your health status before your injury. A condition such as BPPV can be treated effectively in one or two treatment sessions. Injuries that involve many types of impairments can take weeks, months or years. Research shows:

- Most people with TBI are able to walk independently within three months of injury. Although most can return to walking, many continue to have problems with moving quickly and with balance needed to return to high-level activities such as running or sports.
- With hard work, people with TBI can continue to improve their balance for many years after injury but balance problems are still identified more frequently in people with TBI than in people without TBI.

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- Williams GP, Schache AG. Evaluation of a conceptual framework for retraining high-level mobility following traumatic brain injury: two case reports. *J Head Trauma Rehabil.* 2010; 25(3): 164-72.

## Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

## Source

Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the TBI Model System directors.

## Authorship

Balance Problems after TBI was developed by Michelle Peterson, PT, DPT, NCS, and Brian D. Greenwald, MD, in collaboration with the University of Washington Model Systems Knowledge Translation Center.

# Cognitive Problems After Traumatic Brain Injury

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## What is cognition?

Cognition is the act of knowing or thinking. It includes the ability to choose, understand, remember and use information. Cognition includes:

- Attention and concentration.
- Processing and understanding information.
- Memory.
- Communication.
- Planning, organizing, and assembling.
- Reasoning, problem-solving, decision-making, and judgment.
- Controlling impulses and desires and being patient.

## How does TBI affect cognition and what can be done about it?

After a TBI it is common for people to have problems with attention, concentration, speech and language, learning and memory, reasoning, planning and problem-solving.

## Attention and concentration problems

A person with TBI may be unable to focus, pay attention, or attend to more than one thing at a time. This may result in:

- Restlessness and being easily distracted.
- Difficulty finishing a project or working on more than one task at a time.
- Problems carrying on long conversations or sitting still for long periods of time.

Since attention skills are considered a “building block” of higher level skills (such as memory and reasoning), people with attention or concentration problems often show signs of other cognitive problems as well.

## What can be done to improve attention and concentration?

- Decrease the distractions. For example, work in a quiet room.
- Focus on one task at a time.
- Begin practicing attention skills on simple, yet practical activities (such as reading a paragraph or adding numbers) in a quiet room. Gradually make the tasks harder (read a short story or balance a checkbook) or work in a more noisy environment.
- Take breaks when you get tired.

## Problems with processing and understanding information

After brain injury, a person's ability to process and understand information often slows down, resulting in the following problems:

- Taking longer to grasp what others are saying.
- Taking more time to understand and follow directions.
- Having trouble following television shows, movies, etc.
- Taking longer to read and understand written information including books, newspapers or magazines.
- Being slower to react. This is especially important for driving, which may become unsafe if the person cannot react fast enough to stop signs, traffic lights or other warning signs. Individuals with TBI should not drive until their visual skills and reaction time have been tested by a specialist.
- Being slower to carry out physical tasks, including routine activities like getting dressed or cooking.

### What can be done to improve the ability to process and understand information?

- Place your full attention on what you are trying to understand. Decrease distractions.
- Allow more time to think about the information before moving on.
- Re-read information as needed. Take notes and summarize in your own words.
- If needed, ask people to repeat themselves, to say something in a different way, or to speak slower. Repeat what you just heard to make sure you understood it correctly.

## Language and communication problems

Communication problems can cause persons with TBI to have difficulty understanding and expressing information in some of the following ways:

- Difficulty thinking of the right word.

- Trouble starting or following conversations or understanding what others say.
- Rambling or getting off topic easily.
- Difficulty with more complex language skills, such as expressing thoughts in an organized manner.
- Trouble communicating thoughts and feelings using facial expressions, tone of voice and body language (non-verbal communication).
- Having problems reading others' emotions and not responding appropriately to another person's feelings or to the social situation.
- Misunderstanding jokes or sarcasm.

### What can be done to improve language and communication?

Work with a speech therapist to identify areas that need work. Communication problems can keep improving for a long time after the injury.

#### How family members can help:

- Use kind words and a gentle tone of voice. Be careful not to "talk down" to the person.
- When talking with the injured person, ask every so often if he or she understands what you are saying, or ask the person a question to determine if he or she understood what you said.
- Do not speak too fast or say too much at once.
- Develop a signal (like raising a finger) that will let the injured person know when he or she has gotten off topic. Practice this ahead of time. If signals don't work, try saying "We were talking about..."
- Limit conversations to one person at a time.

## Problems learning and remembering new information

- Persons with TBI may have trouble learning and remembering new information and events.
- They may have difficulty remembering events that happened several weeks or months before the injury (although this often comes back over time). Persons with TBI are usually able to remember events that happened long ago.



- They may have problems remembering entire events or conversations. Therefore, the mind tries to “fill in the gaps” of missing information and recalls things that did not actually happen. Sometimes bits and pieces from several situations are remembered as one event. These false memories are not lies.

## What can be done to improve memory problems?

- Put together a structured routine of daily tasks and activities.
- Be organized and have a set location for keeping things.
- Learn to use memory aids such as memory notebooks, calendars, daily schedules, daily task lists, computer reminder programs and cue cards.
- Devote time and attention to review and practice new information often.
- Be well rested and try to reduce anxiety as much as possible.
- Speak with your doctor about how medications may affect your memory.

## Planning and Organization Problems

- Persons with TBI may have difficulty planning their day and scheduling appointments.
- They may have trouble with tasks that require multiple steps done in a particular order, such as laundry or cooking.

## What can be done to improve planning and organization?

- Make a list of things that need to be done and when. List them in order of what should be done first.
- Break down activities into smaller steps.
- When figuring out what steps you need to do first to complete an activity, think of the end goal and work backwards.

## Problems with reasoning, problem-solving and judgment

- Individuals with TBI may have difficulty recognizing when there is a problem, which is the first step in problem-solving.
- They may have trouble analyzing information or changing the way they are thinking (being flexible).
- When solving problems, they may have difficulty deciding the best solution, or get stuck on one solution and not consider other, better options.
- They may make quick decisions without thinking about the consequences, or not use the best judgment.

## What can be done to improve reasoning and problem-solving?

- A speech therapist or psychologist experienced in cognitive rehabilitation can teach an organized approach for daily problem-solving.
- Work through a step-by-step problem-solving strategy in writing: define the problem; brainstorm possible solutions; list the pros and cons of each solution; pick a solution to try; evaluate the success of the solution; and try another solution if the first one doesn't work.

## Inappropriate, embarrassing or impulsive behavior

Individuals with brain injuries may lack self-control and self-awareness, and as a result they may behave inappropriately or impulsively (without thinking it through) in social situations.

- They may deny they have cognitive problems, even if these are obvious to others.
- They may say hurtful or insensitive things, act out of place, or behave in inconsiderate ways.
- They may lack awareness of social boundaries and others' feelings, such as being too personal with people they don't know well or not realizing when they have made someone uncomfortable.

## What causes it?

- Impulsive and socially inappropriate behavior results from decreased reasoning abilities and lack of control. The injured person may not reason that “If I say or do this, something bad is going to happen.”
- Self-awareness requires complex thinking skills that are often weakened after brain injury.

## What can be done about it?

### Things family members can do:

- Think ahead about situations that might bring about poor judgment.
- Give realistic, supportive feedback as you observe inappropriate behavior.
- Provide clear expectations for desirable behavior before events.
- Plan and rehearse social interactions so they will be predictable and consistent.
- Establish verbal and non-verbal cues to signal the person to “stop and think.” For example, you could hold up your hand to signal “stop,” shake your head “no,” or say a special word you have both agreed on. Practice this ahead of time.
- If undesired behavior occurs, stop whatever activity you are doing. For example, if you are at the mall, return home immediately.

## Cognitive outcome/recovery and rehabilitation

Cognition is usually evaluated by a neuropsychologist. Since there are many factors that can affect how someone will improve cognitively, it is very difficult to predict how much someone will recover. With practice, cognitive problems usually improve to some degree.

Cognitive rehabilitation is therapy to improve cognitive skills and has two main approaches, *remediation* and *compensation*:

- *Remediation* focuses on improving skills that have been lost or impaired.
- *Compensation* helps you learn to use different ways to achieve a goal.

## Discuss your concerns with your physician or treatment provider.

You should discuss any questions or concerns you have with a psychiatrist (rehabilitation specialist) or the rehabilitation team. It is important to mention new problems as they develop. New problems could be the result of medication or require further evaluation.

## Recommended reading

- Managing Cognitive Issues, in *Making Life Work after Head Injury*, South Carolina Department of Disabilities and Special Needs.  
[www.state.sc.us/ddsn/pubs/head/issues.htm](http://www.state.sc.us/ddsn/pubs/head/issues.htm)
- Guideposts to Recognition: Cognition, Memory and Brain Injury, in *The Road to Rehabilitation*, Brain Injury Association of America.  
[www.biausa.org/publications/roadToRehab3.pdf](http://www.biausa.org/publications/roadToRehab3.pdf)
- Cognitive and Communication Disorders, in *TBI Resource Guide*, Centre for Neuro Skills.  
[www.neuroskills.com/cogcomm.shtml](http://www.neuroskills.com/cogcomm.shtml)
- Cognitive Rehabilitation, Brain Injury Resource Center.  
[www.headinjury.com/rehabcognitive.html](http://www.headinjury.com/rehabcognitive.html)

## Source

Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the TBI Model Systems.

## Authorship

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# Couples' Relationships After Traumatic Brain Injury

For more information, contact your nearest TBI Model Systems. For a list of TBI Model Systems go to: <http://www.msktc.org/tbi/model-system-centers>

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## Introduction

After traumatic brain injury (TBI), many couples find that their relationship with each other changes dramatically. These changes are very personal and can be very emotional for both people in the relationship. This factsheet will help couples understand some of the common changes they may notice in their relationship after TBI. Also, suggestions are given for ways that couples can address some of the more difficult changes they are experiencing.

Although some of the relationship changes after TBI are difficult and can be painful, there are many things that couples can do in order to enjoy each other and their relationship in new, positive, and meaningful ways.

## Couples' Relationships and TBI

A TBI can significantly change a couple's relationship. There are different degrees of brain injury severity, and milder injuries such as concussions do not always result in significant or long-term relationship changes. However, after severe, moderate, or complicated-mild brain injury, both survivors and their spouses or partners must often change many parts of their lives. The following life changes typically affect intimate relationships:

- Changes in responsibilities
- Changes in relationship roles
- Changes and challenges in communication

Brain injury survivors often have new personality traits, challenges, fears, and limitations. Survivors are often surprised by how these changes also mean that they will feel and behave differently in their relationships. These changes have led many spouses to say they feel like they are "married to a stranger."

The intimate partners of survivors may have new concerns or fears related to both the incident that caused the injury and the new behavior traits of the survivor. Also, partners often change the focus in their lives in order to manage the multiple challenges that arise for their family after an injury.

These changes in the survivor's personality and the life focus of both partners often result in a feeling that partners do not know what to expect from one another. Uncertainty can increase stress and anxiety within the home.



## How Are Relationships Typically Affected?

### Responsibilities

After a TBI, survivors must focus their energy on getting better and developing new skills. As a result, the assignment of responsibilities in the home must change. This means that everyone in the family is involved in learning new skills and taking on new jobs.

### How do responsibilities typically change?

- Survivors often give up many responsibilities, including work expectations and household chores, while they focus on getting better.
- Partners often must take on many responsibilities formerly managed by the survivor, such as:
  - Yard work and physically maintaining their home through chores and repairs
  - Managing household finances
  - Planning and organizing activities for the family
- There are also new tasks for both survivors and their partners, such as managing the health care of the survivor.

### What happens when responsibilities change?

- Any time people have to take on new responsibilities and learn how to handle new tasks, they will also experience more stress.
- In addition to the stress of injury and recovery, the stress of changes in responsibilities can increase tension between partners.
- Partners who have significantly more responsibilities will also have less time for other things. In contrast, survivors who are focusing on getting better may feel like they have more time. This can result in different expectations about how much time partners have to spend together.

### Tips to improve relationship issues related to responsibility changes

- Be understanding about each other's new responsibilities. This can have a positive

impact on a relationship. Although it is natural to focus on oneself when a person is overwhelmed, partners must take time and effort to note all of the new responsibilities their partner is managing. Noticing and talking about these challenges can reduce tension within your relationship.

- Say "thank you." Make a commitment to yourself to thank your partner at least once a day for attempting to manage new responsibilities.
- Schedule opportunities to take breaks from responsibility. These breaks may be short and may not be as frequent as desired. However, when couples and families schedule time off for each adult family member and honor that commitment both practically and emotionally, thankfulness and respect are more likely to grow in the relationship.

## Relationship Roles

In all families, people take on roles that often define how they behave. After brain injury, the challenge of recovery nearly always results in some changes to the roles within a family. While the person with TBI is in the hospital, their partner may need to make decisions that are usually made by the survivor. For example, a husband may make decisions about child care that his wife usually makes, or a wife may calm the family when everyone is upset, although that is something her husband has always done.

### How do relationship roles change?

- Although people often take on many different roles in their relationships over the course of a lifetime, TBI results in dramatic role changes that occur instantly, and without preparation.
- Early on in recovery, it may seem to couples that role changes are temporary. However, as time progresses, couples often find that these role changes may last for years or even be permanent.
- Commonly, partners take on more leadership roles in the relationship. Depending upon who is hurt and how the family did things before the injury, this may mean some small shifts for the couple, or it may mean drastic changes.

## What happens when relationship roles change?

- The more role changes that occur, and the more dramatic the changes are, the harder it may be for a couple to adjust to the changes.
- Certain family dynamics may also make the role changes more challenging:
  - Couples who keep tasks separate instead of alternating who does what may find it more challenging to adjust to new roles.
  - Couples who have just recently begun a new phase of their relationship, such as being newly married, having children, or being a new “empty nest” couple, may have a more difficult time with changes in roles.
- As each partner learns how to operate in his or her new role, there will be a period of adjustment for both people. Uncertainty and frustration during this time can result in increased criticism between partners.
- People close to the couple may not understand the need for role changes and sometimes incorrectly believe that such changes slow recovery. For example, family members may say “Let her talk to the kids’ teachers. She will never get back to her old self if you don’t let her do her job.” This can cause tension between the couple and their family and/or friends.

## Tips to improve relationships when roles have changed

- Identify where role changes occur and talk about these changes openly. Partners should try to be sensitive to the feelings of survivors. For example, the survivor may have felt pride in his or her role before the TBI and may feel sad or frustrated when asked to step aside.
- Partners can serve as mentors and consultants for one another. Couples can ask one another, “What works best for you when you are in this situation?” Although survivors may not be able to manage a former role, such as being the financial decision maker, they can share their knowledge with their spouse. Both partners will benefit when this approach is taken.
- Couples must be conscious of not criticizing the partner who is taking on a new role. For example, it is unlikely that a girlfriend will handle a challenge in the same way her

boyfriend would have handled it. Partners should work hard to support one another in their new roles. This includes being patient with the time it takes for everyone to feel comfortable in their new roles.

- Family and friends may need to be taught about brain injury and the changes it brings. Children who live at home will also benefit from direct discussions about these changes: “I know mom used to be the person who checked your homework every day, but she and I have decided that it will be better for now if I do it.” Without open communication about role changes, others may not understand why things feel so different and why supporting those differences can help the whole family to heal.

## Communication

Communication is the foundation of a relationship. Many people think only of talking when they hear the word “communication,” but couples are actually communicating through gestures, facial expressions, emotional reactions, and physical interactions as well. In studies on relationships after brain injury, communication is often reported as the biggest change people notice.

### For spouses:

- Additional responsibilities and the uncertainty of recovery can cause spouses to feel very overwhelmed. When overwhelmed, people often change their communication styles. Some common changes can include: talking less, talking more, and/or communicating more intensely or urgently than before.
- Spouses may be unsure how best to communicate with their partner after injury. This discomfort may cause spouses not to communicate as often or as openly with the survivor.

### For both people:

- Increased stress levels often affect communication for both partners.
- Both people may be afraid that sharing their negative thoughts or feelings will burden their partner.

- When either person in a relationship changes how he or she communicates, both people will behave differently.

## What happens when communication styles and patterns change?

- Changes in communication between partners can result in both people feeling alone and isolated. Couples may feel they no longer understand what their partner is thinking or feeling.
- Difficulty communicating can sometimes cause people to pull away from their relationship, choosing instead to handle challenges with friends or other family members. Sometimes, people choose not to communicate their feelings with anyone at all.
- Communication struggles can impact all other parts of a relationship, including responsibilities and roles, and make it difficult to adjust to changes together.

## Tips on improving a couple's communication

- Both partners should make a commitment to improve communication.
- Listen patiently to what your partner is saying.
- Listen for points where you can agree rather than focusing on disagreement.
- When you do disagree, think about what you might say before you say it.
- Remember that survivors will likely need more time to think about what their partner is saying, or about how they want to communicate—again, patience is key.
- Take notes on your thoughts during conversations rather than immediately saying what comes to mind. Come back to these points later, after you have had time to reflect.
- Exchange bulleted lists of important points for big discussions. When you have something you would like to say, write it down before a discussion and use it as a guide. Trading these lists after a conversation helps with memory and allows more time to digest and think about the information.
- When a topic is likely to cause a disagreement, practice what you would like to say before you start the conversation.

- Practice in front of a mirror. Look at facial expressions, gestures, and body language while also choosing your words carefully. When you talk, try to stick to what you practiced.

## Physical Intimacy/Sexual Relationships

Most couples notice significant changes in their sexual relationship after TBI.\*There are many reasons for these differences, including changes in:

- Hormone levels due to injury
- Roles in the sexual relationship
- Appearance, self-confidence, and or attraction
- Areas of sexual interest

*\*For more information on physical intimacy and sex after TBI, see the MSKTC factsheet "TBI & Sexuality."*

## Tips for Improving Intimate Relationships

### Find a therapist

Therapy can give couples support and ideas to improve their specific situations. Different types of counseling are available, including individual counseling for either the survivor or partner, couples' counseling, or family therapy.

Seek out a counselor or psychotherapist who has expertise in brain injuries. If there are no therapists locally with brain injury experience, couples should provide their therapist with information about injury and common relationship challenges that can accompany injury. The Web sites on this factsheet can be a good place to start.

### Try a support group

Many communities have support groups for both survivors and caregivers/partners, which are often listed in the newspaper or advertised by State brain injury associations.

These groups can help couples establish new friendships, find local information and resources, and provide time apart from their partner for reflection.

When local support groups are unavailable, try Web-based chat groups and support communities. These groups are an excellent option when in-person groups are either too far away or when transportation is a challenge.

## Finding a therapist or a support group

To find a support group or counselor in your area, start with your State brain injury association. If you do not know how to reach your State brain injury association you can either: a) contact the Brain Injury Association of America (1-800-444-6443 or on the Web at <http://www.biausa.org>) or b) use an online search engine (Google, Yahoo, Bing, etc.) to find one by typing in “Brain Injury Association” and the name of your state.

Online support groups are available on Facebook, and throughout the Web. Use the search feature on Facebook and type “Traumatic Brain Injury” to find different groups that you may like. Or use an online search engine such as Google or Yahoo and search the term “Traumatic Brain Injury Support Groups.” There are many different options, so look around to find the one that best fits your needs.

## Changing the relationship environment

At home, make a commitment to establish a positive environment. Looking for progress in recovery instead of ways in which a relationship is not succeeding can improve how people feel about each other. Additionally, part of having a positive home life comes from the opportunity for fun as a couple.

Scheduling a “date” on the calendar to take a walk, watch a movie on television, or play a game like cards can be an inexpensive strategy that may make a big difference in reducing tension. When fun time is scheduled, consider it to be as important as a doctor’s appointment—something that cannot be ignored or rescheduled.

## Considerations in new relationships

If you are in a new relationship, the process of recovery can be more complicated. For example, if an individual is injured while he or she is in the early stages of a relationship, the couple may not know what their roles are yet.

This can result in confusion and uncertainty and may lead some people to ask, “Who am I in this relationship?” or “Who are we together?”

Any couples who are new to their relationships can work to take a positive approach to recovery. Although role uncertainty may be a challenge, it also provides the couple more freedom by not being tied to old ways of doing things.

## Considerations in nontraditional relationships

There are also a growing number of adults who choose to live in unmarried monogamous relationships. For cultural, financial, social, or other reasons, these couples may not be in a “traditional marriage.” Individuals who identify as gay, bisexual, lesbian, or transgender, as well as people who identify as heterosexual and in an unmarried relationship may have more complicated issues to deal with.

For example, they may not have access to their unmarried partner’s insurance, bereavement, pension, or other benefits. Other challenges can include the inability to be represented in health care decisions, lack of recognized family leave from work, or even having to choose to “come out” as a result of the injury. In addition, the lack of acceptance or awareness in their community with regard to nontraditional relationships may impact a couple’s ability even to seek or obtain care. These complications can influence a couple’s success or failure in a relationship.

## Tips for nontraditional couples to manage challenges

- For caregiving partners, building relationships with the survivor’s family members who are supportive can be very helpful.

Partners may want to make working on these relationships a top priority as a way to stay involved in a survivor's care.

- Psychotherapy or counseling is likely an important component of recovery for nontraditional couples. Because partners may have even less support than couples in traditional relationships, finding a therapist who can provide this support and guidance is an important part of healing.

## Concerns About Divorce or Separation

You may have heard that divorce or separation is likely after TBI. Although no one knows for sure what will happen in any relationship, some studies suggest that divorce and separation rates may actually be lower after brain injury than for the rest of the population. Rather than focusing on the possibility of divorce or separation, couples do best by focusing on improving the quality of their relationship with one another.

## Recommended Reading

- *Healing Your Marriage After Brain Injury.* Published in "The Challenge," a Brain Injury Association of America publication. Written by Jeffrey S. Kreutzer, Ph.D., and Emilie E. Godwin, Ph.D.
- *Learning by Accident.* Written by Rosemary Rawlins
- *Brain Injury Survivor's Guide: Welcome to Our World.* Written by Larry Jameson and Beth Jameson
- Blog: *Starting Marriage Over After a Brain Injury (survivor and caregiver stories).* Available at - <http://www.marriagemissions.com/starting-marriage-over-after-a-brain-injury/>

## Source

Our health information content is based on research evidence and approved by experts from the TBI Model Systems.

## Authorship

*Couples' Relationships After Traumatic Brain Injury* was developed by Emilie Godwin, Ph.D., Jeffrey Kreutzer, Ph.D., and Stephanie Kolakowsky-Hayner, Ph.D., in collaboration with the Model Systems Knowledge Translation Center.



# Depression after Traumatic Brain Injury

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## What is depression?

Depression is a feeling of sadness, loss, despair or hopelessness that does not get better over time and is overwhelming enough to interfere with daily life. There is cause for concern when feeling depressed or losing interest in usual activities occurs at least several days per week and lasts for more than two weeks.

## Symptoms of depression include:

- Feeling down, sad, blue or hopeless.
- Loss of interest or pleasure in usual activities.
- Feeling worthless, guilty, or that you are a failure.
- Changes in sleep or appetite.
- Difficulty concentrating.
- Withdrawing from others.
- Tiredness or lack of energy.
- Moving or speaking more slowly, or feeling restless or fidgety.
- Thoughts of death or suicide.

Feeling sad is a normal response to the losses and changes a person faces after TBI. However, prolonged feelings of sadness or not enjoying the things you used to enjoy are often key signs of depression, especially if you also have some of the other symptoms listed above.

## How common is depression after TBI?

Depression is a common problem after TBI. About half of all people with TBI are affected by depression within the first year after injury. Even more (nearly two-thirds) are affected within seven years after injury. In the general population, the rate of depression is much lower, affecting fewer than one person in 10 over a one-year period. More than half of the people with TBI who are depressed also have significant anxiety.

## What causes depression after TBI?

Many different factors contribute to depression after TBI, and these vary a great deal from person to person.

- **Physical changes in the brain due to injury.**  
Depression may result from injury to the areas of the brain that control emotions. Changes in the levels of certain natural chemicals in the brain, called neurotransmitters, can cause depression.
- **Emotional response to injury.**  
Depression can also arise as a person struggles to adjust to temporary or lasting disability, losses or role changes within the family and society.
- **Factors unrelated to injury.**  
Some people have a higher risk for depression due to inherited genes, personal or family history, and other influences that were present before the brain injury.

## What can be done about depression after TBI?

If you have symptoms of depression, it is important to seek professional help as soon as possible, preferably with a health care provider who is familiar with TBI. Depression is not a sign of weakness, and it is not anyone's fault. Depression can be a medical problem, just like high blood pressure or diabetes. You cannot get over depression by simply wishing it away, using more willpower or "toughening up." It is best to get treatment early to prevent needless suffering and worsening symptoms.

If you have thoughts of suicide, get help right away. **If you have strong thoughts of suicide and a suicide plan, call a local crisis line, 911, the 24-hour National Crisis Hotline at 800-273-8255, or go to an emergency room immediately.**

The good news is that certain antidepressant medications and psychotherapy (counseling) treatments, or a combination of the two, can help most people who have depression.

## Medications

Antidepressant medications work by helping to re-balance the natural chemicals (called neu-

rotransmitters) in the brain. Antidepressants are not "addictive."

It is also important to know that even if antidepressants help with depression, they usually do not have to be taken forever. Sometimes a medication can help re-balance the brain's chemistry and can eventually be discontinued (for example, after 6-12 months). However, each person's situation is unique, and both taking and discontinuing antidepressants should always be done under a doctor's supervision.

In addition to helping with mood, antidepressants can also help with the other symptoms of depression, such as low energy, poor concentration, poor sleep and low appetite. Some antidepressants can also help with anxiety symptoms.

There are many different types or "classes" of antidepressant medications. Studies of depression in TBI have found that some classes may work better than others.

- **Selective serotonin reuptake inhibitors, commonly called SSRIs**, have been found to be the most effective antidepressants for people with TBI. Specifically, sertraline (Zoloft®) and citalopram (Celexa®) may have the fewest side effects and may even improve cognition (thinking ability).
- **Serotonin-norepinephrine reuptake inhibitors, or SNRIs**, such as venlafaxine (Effexor®) are newer drugs that also may be a good option for people with TBI.
- Some types of antidepressants should be **avoided** in most cases because they have side effects that can cause problems in people with TBI. These include monoamine oxidase inhibitors (MAOIs). Tricyclic antidepressants (TCAs) are often used safely at low doses for sleep or pain, but may cause side effects at higher doses.

After starting antidepressants, it can take a few weeks to feel better. Sometimes your physician will need to change the dose over time or switch to a different medication if one doesn't work well enough. In some cases, two different antidepressants can be used together if a single medication is not effective.

It is important to take antidepressant medication every day, even if you are feeling better. Do not stop it abruptly. In most cases, your physician will recommend taking the medication for at least several months.

## Psychotherapeutic (counseling) approaches

There are many different kinds of psychotherapy and counseling. For people with depression, the most effective types of therapy are those that focus on day-to-day behavior and thinking.

**Cognitive-behavioral therapy or CBT** helps people learn how to change the way they behave, think and feel about things that happen to them, and the way they see themselves. CBT has reduced depression in the general population and is currently being tested to determine the best ways to adapt it for people who have the types of thinking and memory problems that can happen with TBI.

**Behavioral activation therapy** helps people with depression become more active and begin to enjoy doing pleasurable activities again. This increased activity helps to improve mood. A professional counselor can help you set up a routine of pleasurable activity and evaluate the effects on your mood.

Remember, many people do best with a combination of approaches, such as antidepressant medication plus sessions with a trained counselor to work on changing behavior.

## Other treatment approaches

Other approaches such as exercise, acupuncture and biofeedback have been shown to be helpful in treating depression in the general population. Some people with TBI also find them helpful. A professional specializing in TBI should be consulted about these treatments. Treating anxiety and pain can also help to reduce depression. Brain injury support groups may be a good source of additional information and support for depression and other challenges following a TBI.

## How to find help

- Many mental health professionals are qualified to treat depression. Psychiatrists have special-

ized training in medication management and counseling for depression, and psychologists are trained to provide counseling for depression. Some social workers and licensed professional counselors are also trained to provide counseling for depression.

- Physicians—such as primary care physicians, neurologists and psychiatrists—and nurse practitioners with experience in treating depression can often get treatment started.
- When available, it is best to get treatment from a comprehensive brain injury rehabilitation program that can address all aspects of TBI recovery.
- For more general information about depression, contact the National Institute of Mental Health at 1-866-615-6464 (toll-free) or online at <http://www.nimh.nih.gov/health/topics/depression/index.shtml>.

## References

Fann, J.R., Hart, T., Schomer, K.G.. Treatment for Depression after Traumatic Brain Injury: A Systematic Review. *Journal of Neurotrauma* 26:2383-2402, 2009

## Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

## Source

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## Authorship

*Depression after Traumatic Brain Injury* was developed by Jesse Fann, MD, MPH, and Tessa Hart, PhD, in collaboration with the University of Washington Model Systems Knowledge Translation Center.



# Driving after Traumatic Brain Injury

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Driving is an important part of a person's independent lifestyle and integration into the community. Because we take our driving skills for granted, it is easy to forget that driving is the most dangerous thing we do in our everyday lives. A brain injury can affect the skills needed to drive safely. If and when an injured person may safely return to driving should be addressed early in recovery. The injured person, family members, and health professionals should all be included in this important decision. If anyone has concerns that that driving may put the injured person or others in danger, health professionals may recommend pre-driving testing.

## How can a TBI affect driving ability?

A brain injury can disrupt and slow down skills that are essential for good driving, such as:

- Ability to maintain a constant position in a lane.
- Having accurate vision.
- Maintaining concentration over long periods of time.
- Memory functioning, such as recalling directions.
- Figuring out solutions to problems.
- Hand-eye coordination.
- Reaction time.
- Safety awareness and judgment.

Studies indicate that even mild thinking difficulties, which may not be recognized by the injured person, may add to increased risks while driving.

## Warning signs of unsafe driving

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

## How often do individuals with TBI return to driving?

Between 40 and 60 percent of people with moderate to severe brain injuries return to driving after their injury. To lessen the risk of crashes, people with TBI may place limitations on their driving habits. They may drive less frequently than they did before the injury or drive only at certain times (such as during daylight), on familiar routes, or when there is less traffic. Having experienced a seizure after the TBI may be a barrier to driving. States often require that a person be free of seizures for a period of time, such as 6 months, before resuming driving. People who want to return to driving need to check with the laws in their state.

## Driving evaluations and training

A driving evaluation is a crucial step in determining a person's ability to drive following recovery from a TBI. Research studies indicate that most TBI survivors are not thoroughly evaluated for driving skills before they begin driving after the injury, and this may put TBI survivors at risk for a crash.

While there is no standardized assessment test or process, a typical driving evaluation has two parts:

- **Preliminary Evaluation:** A review of cognitive (thinking) abilities, including reaction time, judgment, reasoning and visual spatial skills. Recommendations regarding the need for adaptive equipment and additional skills training are based on the results of the evaluation.
- **On-the-Road:** A test of the mechanical operation of a vehicle, either using a driving simulator or driving a vehicle on the roadway in the presence of the evaluator. This evaluation is used to assess safe driving skills in various traffic environments, as well as basic driving skills while a client uses the appropriate adaptive driving equipment.

Current research indicates that many individuals with TBI can become competent, safe drivers

when given the proper training. Training serves to improve specific driving skills. Sometimes this involves practicing driving under the supervision of a driving evaluator. In some cases a training program might focus on specific skills such as rapid understanding of visual information.

Evaluations and training are often provided by professionals certified through the Association for Driver Rehabilitation (ADED). A list of certified professionals may be found on the ADED website, [www.driver-ed.org](http://www.driver-ed.org).

## Vehicle modifications

If an individual with TBI has physical disabilities but has well-preserved cognitive functions, the individual may be able to resume driving with adaptive equipment and/or other modifications to the vehicle.

Recommendations for adaptive equipment and modifications could include:

- Hand-controlled gas and brake systems.
- Spinner knobs for steering.
- Left foot accelerator.
- Lifts for entering and exiting the vehicle.

## Legal and insurance considerations

A person who wishes to resume driving must have a valid driver's license. In some states there must be a formal evaluation performed by a licensing bureau before resuming driving after a brain injury. Insurance may also be required. The person should check local regulations relating to licenses and insurance.

## Other transportation options

Accessible and reliable transportation is the most critical part of community integration following a TBI. If a person is not able to drive, there may be other options for transportation. Family members can provide transportation, and public transportation such as buses can be used. Some communities provide public transportation specifically for disabled riders.

## Step-by-Step: Should you be driving?

1. Discuss your ability to drive with your doctor and/or health professionals, family members
2. Get a professional evaluation to determine your driving ability
3. Based on your evaluation you may be allowed to drive, need training or vehicle modification before returning to driving, or will need to use other transportation options

## Recommended resources

- Brain Injury Association of America. [www.biausa.org](http://www.biausa.org)
- State Vocational Rehabilitation Offices. [www.jan.wvu.edu](http://www.jan.wvu.edu)
- Association for Driver Rehabilitation Specialists. [www.driver-ed.org](http://www.driver-ed.org)
- National Mobility Equipment Dealers Association. [www.nmeda.org](http://www.nmeda.org)

## Reference

Eby, D.W., Molnar, L. J. (2010) Driving Fitness and Cognitive Impairment. *JAMA*. 303(16):1642-1643.

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## Source

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## Authorship

# Emotional Problems after Traumatic Brain Injury

For more information, contact your nearest TBI Model Systems. For a list of TBI Model Systems go to: <http://www.msktc.org/tbi/model-system-centers>

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A brain injury can change the way people feel or express emotions. An individual with TBI can have several types of emotional problems.

### Difficulty controlling emotions or “mood swings”

Some people may experience emotions very quickly and intensely but with very little lasting effect. For example, they may get angry easily but get over it quickly. Or they may seem to be “on an emotional roller coaster” in which they are happy one moment, sad the next and then angry. This is called *emotional lability*.

#### What causes this problem?

- Mood swings and emotional lability are often caused by damage to the part of the brain that controls emotions and behavior.
- Often there is no specific event that triggers a sudden emotional response. This may be confusing for family members who may think they accidentally did something that upset the injured person.
- In some cases the brain injury can cause sudden episodes of crying or laughing. These emotional expressions or outbursts may not have any relationship to the way the person feels (in other words, they may cry without feeling sad or laugh without feeling happy). In some cases the emotional expression may not match the situation (such as laughing at a sad story). Usually the person cannot control these expressions of emotion.

#### What can be done about it?

- Fortunately, this situation often improves in the first few months after injury, and people often return to a more normal emotional balance and expression.
- If you are having problems controlling your emotions, it is important to talk to a physician or psychologist to find out the cause and get help with treatment.
- Counseling for the family can be reassuring and allow them to cope better on a daily basis.
- Several medications may help improve or stabilize mood. You should consult a physician familiar with the emotional problems caused by brain injury.

## What family members and others can do:

- Remain calm if an emotional outburst occurs, and avoid reacting emotionally yourself.
- Take the person to a quiet area to help him or her calm down and regain control.
- Acknowledge feelings and give the person a chance to talk about feelings.
- Provide feedback gently and supportively after the person gains control.
- Gently redirect attention to a different topic or activity.

## Anxiety

Anxiety is a feeling of fear or nervousness that is out of proportion to the situation. People with brain injury may feel anxious without exactly knowing why. Or they may worry and become anxious about making too many mistakes, or “failing” at a task, or if they feel they are being criticized. Many situations can be harder to handle after brain injury and cause anxiety, such as being in crowds, being rushed, or adjusting to sudden changes in plan.

Some people may have sudden onset of anxiety that can be overwhelming (“panic attacks”). Anxiety may be related to a very stressful situation—sometimes the situation that caused the injury—that gets “replayed” in the person’s mind over and over and interferes with sleep (“post traumatic stress disorder”). Since each form of anxiety calls for a different treatment, anxiety should always be diagnosed by a mental health professional or physician.

## What causes anxiety after TBI?

- Difficulty reasoning and concentrating can make it hard for the person with TBI to solve problems. This can make the person feel overwhelmed, especially if he or she is being asked to make decisions.
- Anxiety often happens when there are too many demands on the injured person, such as returning to employment too soon after injury. Time pressure can also heighten anxiety.

- Situations that require a lot of attention and information-processing can make people with TBI anxious. Examples of such situations might be crowded environments, heavy traffic or noisy children.

## What can be done about anxiety?

- Try to reduce the environmental demands and unnecessary stresses that may be causing anxiety.
- Provide reassurance to help calm the person and allow them to reduce their feelings of anxiety when they occur.
- Add structured activities into the daily routine, such as exercising, volunteering, church activities or self-help groups.
- Anxiety can be helped by certain medications, by psychotherapy (counseling) from a mental health professional who is familiar with TBI, or a combination of medications and counseling.

## Depression

Feeling sad is a normal response to the losses and changes a person faces after TBI. Feelings of sadness, frustration and loss are common after brain injury. These feelings often appear during the later stages of recovery, after the individual has become more aware of the long-term situation. If these feelings become overwhelming or interfere with recovery, the person may be suffering from depression.

Symptoms of depression include feeling sad or worthless, changes in sleep or appetite, difficulty concentrating, withdrawing from others, loss of interest or pleasure in life, lethargy (feeling tired and sluggish), or thoughts of death or suicide.

Because signs of depression are also symptoms of a brain injury itself, having these symptoms doesn’t necessarily mean the injured person is depressed. The problems are more likely to mean depression if they show up a few months after the injury rather than soon after it.

## What causes depression?

- Depression can arise as the person struggles to adjust to temporary or lasting disability and loss or to changes in one’s roles in the family and society caused by the brain injury.

- Depression may also occur if the injury has affected areas of the brain that control emotions. Both biochemical and physical changes in the brain can cause depression.

## What can be done about depression?

- Anti-depressant medications, psychotherapy (counseling) from a mental health professional who is familiar with TBI, or a combination of the two, can help most people who have depression.
- Aerobic exercise and structured activities during each day can sometimes help reduce depression.
- Depression is not a sign of weakness, and it is not anyone's fault. Depression is an illness. A person cannot get over depression by simply wishing it away, using more willpower or "toughening up."
- It is best to get treatment early to prevent needless suffering. Don't wait.

## Temper outbursts and irritability

Family members of individuals with TBI often describe the injured person as having a "short fuse," "flying off the handle" easily, being irritable or having a quick temper. Studies show that up to 71% of people with TBI are frequently irritable. The injured person may yell, use bad language, throw objects, slam fists into things, slam doors, or threaten or hurt family members or others.

## What causes this problem?

Temper outbursts after TBI are likely caused by several factors, including:

- Injury to the parts of the brain that control emotional expression.
- Frustration and dissatisfaction with the changes in life brought on by the injury, such as loss of one's job and independence.
- Feeling isolated, depressed or misunderstood.
- Difficulty concentrating, remembering, expressing oneself or following conversations, all of which can lead to frustration.
- Tiring easily.
- Pain.

## What can be done about temper problems?

- Reducing stress and decreasing irritating situations can remove some of the triggers for temper outbursts and irritability.
- People with brain injury can learn some basic anger management skills such as self-calming strategies, relaxation and better communication methods. A psychologist or other mental health professional familiar with TBI can help.
- Certain medications can be prescribed to help control temper outbursts.

## Family members can help by changing the way they react to the temper outbursts:

- Understand that being irritable and getting angry easily is due to the brain injury. Try not to take it personally.
- Do not try to argue with the injured person during an outburst. Instead, let him or her cool down for a few minutes first.
- Do not try to calm the person down by giving in to his or her demands.
- Set some rules for communication. Let the injured person know that it is not acceptable to yell at, threaten or hurt others. Refuse to talk to the injured person when he or she is yelling or throwing a temper tantrum.
- After the outburst is over, talk about what might have led to the outburst. Encourage the injured person to discuss the problem in a calm way. Suggest other outlets, such as leaving the room and taking a walk (after letting others know when he/she will return) when the person feels anger coming on.

## Questions to ask your physician or treatment provider to better understand your problem

If you or your family members are experiencing anxiety, feelings of sadness or depression, irritability or mood swings, consider asking your doctor:

- Would psychological counseling be helpful?
- Would an evaluation by a psychiatrist be helpful?



- Are there medications that can help?

## More about medications

If you or your family member tries a medication for one of these problems, it is very important to work closely with the physician or other health care provider who prescribes them. Always make a follow-up appointment to let him or her know how the medication is working, and report any unusual reactions between appointments. Remember that:

- There can be a delay until the beneficial effects of medications are felt.
- Doses might need to be adjusted by your doctor for maximum benefit.
- You may need to try one or more different medications to find the one that works best for you.
- Except in an emergency, you should not stop taking a prescribed medication without consulting your doctor.

## Peer and other support

Remember, too, that not all help comes from professionals! You may benefit from:

- A brain injury support group — some are specialized for the person with TBI, others are for family members, and others are open to everyone affected by brain injury.
- Peer mentoring, in which a person who has coped with brain injury for a long time gives support and suggestions to someone who is struggling with similar problems.
- Check with your local Brain Injury Association chapter to find out more about these resources. Go to <http://www.biausa.org/> to find brain injury resources near you.
- Talk to a friend, family member, member of the clergy or someone else who is a good listener.

## Recommended reading

- *Living with Brain Injury: A Guide for Families, Second Edition* (Paperback) by Richard C Senelick and Karla Dougherty, Healthsouth Press, 2001.

- *Making Life Work After Head Injury: A Family Guide for Life at Home*. Author: South Carolina, Head and Spinal Cord Injury Division, and National Head Injury Foundation (U.S.), Florida Association. Publisher: S.C. Dept. of Disabilities and Special Needs, Head and Spinal Cord Injury Division, 1994.
- *What is Brain Injury? Emotional / Behavioral Changes*, Toronto Acquired Brain Injury Network. [www.abinetwork.ca/familyresourceguide/whatisbraininjury-behavioural.htm](http://www.abinetwork.ca/familyresourceguide/whatisbraininjury-behavioural.htm)
- Emotional Stages in Recovery – Fact Sheet. Brain Injury Association of Queensland, Inc. <http://braininjury.org.au/portal/post-acute-phase/emotional-stages-in-recovery—fact-sheet.html>
- Involuntary Emotional Expression Disorder (IEED): Explaining Unpredictable Emotional Episodes. National Stroke Association. [www.stroke.org/site/PageServer?pagename=IEED](http://www.stroke.org/site/PageServer?pagename=IEED)

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## Source

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## Authorship

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# Fatigue and Traumatic Brain Injury

## What is fatigue?

Fatigue is a feeling of exhaustion, tiredness, weariness or lack of energy. After TBI, you may have more than one kind of fatigue:

1. Physical fatigue: “I’m tired and I need to rest. I’m dragging today.”
2. Psychological fatigue: “I just can’t get motivated to do anything. Being depressed wears me out; I just don’t feel like doing anything.”
3. Mental fatigue: “After a while, I just can’t concentrate anymore. It’s hard to stay focused. My mind goes blank.”

## Why is fatigue important?

When you are fatigued, you are less able to think clearly or do physical activities. If you are overwhelmed by fatigue, you have less energy to care for yourself or do things you enjoy. Fatigue can have a negative effect on your mood, physical functioning, attention, concentration, memory and communication. It can interfere with your ability to work or enjoy leisure activities. It can make activities such as driving dangerous.

## How common is fatigue after TBI?

Fatigue is one of the most common problems people have after a traumatic brain injury. As many as 70% of survivors of TBI complain of mental fatigue.

## What causes fatigue?

Fatigue is normal for anyone after hard work or a long day. In persons with TBI, fatigue often occurs more quickly and frequently than it does in the general population. The cause of fatigue after TBI is not clear but may be due to the extra effort and attention it takes to do even simple activities such as walking or talking clearly. Brain function may be less “efficient” than before the injury.

- **Physical fatigue** can come from muscle weakness. The body needs to work harder to do things that were easy before the TBI. Physical fatigue gets worse in the evening and is better after a good night’s sleep. Often this kind of fatigue will lessen as the individual gets stronger, more active and back to his or her old life.
- **Psychological fatigue** is associated with depression, anxiety and other psychological conditions. This type of fatigue gets worse with stress. Sleep may not help at all, and the fatigue is often at its worst when you wake up in the morning.



- **Mental fatigue** comes from the extra effort it takes to think after your brain is injured. Many common tasks take much more concentration than they did before. Working harder to think and stay focused can make you mentally tired.
- **Certain conditions are known to cause or increase fatigue:**
  - Depression
  - Sleep problems, such as sleep apnea
  - Seasonal allergies
  - Hypothyroidism or other endocrine gland disorders
  - Respiratory or cardiac problems
  - Headaches
  - Lack of physical exercise
  - Vitamin deficiency/poor nutrition
  - Stress
  - Low red blood cell counts (anemia)
  - Medications commonly used after TBI, such as muscle relaxers and pain medication
- **Improve your time management:**
  - Plan and follow a daily schedule. Using a calendar or planner can help manage mental fatigue.
  - Prioritize activities. Finish what is most important first.
  - Do things that require the most physical or mental effort earlier in the day, when you are fresher.
  - Avoid over-scheduling.
  - If visitors make you tired, limit time with them.
- **Exercise daily.** Research has shown that people with TBI who exercise have better mental function and alertness. Over time, exercise and being more active helps lessen physical and mental fatigue and builds stamina. It also may decrease depression and improve sleep.
- **Talk to your doctor.**
  - Discuss medical or physical problems that may be causing fatigue.
  - Have your doctor review all your current medications.
  - Tell your doctor if you think you might be depressed so treatment can be started.
  - Ask your doctor if there are any blood tests that could help to find out what is causing your fatigue.

## What can be done to decrease fatigue?

- **Pay attention to what triggers your fatigue**, and learn to identify the early signs of fatigue, such as becoming more irritable or distracted. Stop an activity before getting tired.
- **Get more sleep and rest.** If you have insomnia, tell your doctor. There may be a medical condition causing this, or there may be useful treatments.
- **Set a regular schedule** of going to bed and awakening the same time every day: your body and mind will be more efficient. Include some regular rest breaks or naps. Be careful to limit naps to 30 minutes and avoid evening naps.
- **Alcohol and marijuana** will generally make fatigue worse.
- **Caffeine** (coffee, cola products) should be avoided after lunch if sleeping is a problem
- **Resume activities gradually**, over weeks or even months.
- **Start with familiar tasks** at home or work that you can complete without fatigue. Gradually increase the complexity of each task, taking breaks as needed.

## Source

Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the TBI Model Systems.

## Authorship

# Headaches after Traumatic Brain Injury

Headache is one of the most common symptoms after traumatic brain injury (often called “post-traumatic headache”). Over 30% of people report having headaches which continue long after injury.

## Why are headaches a problem after brain injury?

Headaches after TBI can be long-lasting, coming and going even past one year. Headaches can make it hard for you to carry out daily activities or can cause you to have more difficulty thinking and remembering things.

## Why do headaches happen after brain injury?

Right after a severe TBI, people may have headaches because of the surgery on their skulls or because they have small collections of blood or fluid inside the skull.

Headaches can also occur after mild to moderate injury or, in the case of severe TBI, after the initial healing has taken place. These headaches can be caused by a variety of conditions, including a change in the brain caused by the injury, neck and skull injuries that have not yet fully healed, tension and stress, or side effects from medication.

## What are some typical kinds of headaches after TBI?

### Migraine headaches

These kinds of headaches happen because an area of the brain becomes hypersensitive and can trigger a pain signal that spreads out to other parts of the brain (like the ripples that spread out after you drop a pebble in water). These headaches typically have the following features:

- Dull, throbbing sensation, usually on one side of the head.
- Nausea or vomiting.
- Light and sound sensitivity.
- Pain level rated as moderate to severe.
- You might get a “warning” signal that a migraine is coming on, such as seeing spots or bright lights. This is called an “aura.”

### Tension-type headaches

These headaches are associated with muscle tension or muscle spasms and stress. They usually have the following features:

- Tight, squeezing sensation, often around the entire head or on both sides.

- Pain level rated as mild to moderate.
- Occur later in the day.

## Cervicogenic headaches

This type of headache can occur when there has been some injury to the muscles and soft tissues in the neck and the back of the head. Many nerves that are located in the tissues and bones of the neck have branches that travel to the skull and scalp and can result in head pain. This type of headache usually has these features:

- Often start in the neck, shoulders and back of the head, and sometimes travel over the top of the head.
- Neck movement or positioning can make the pain worse.
- These headaches are not usually associated with nausea and can range from mild to severe.

## Rebound headaches

Sometimes the very medicines used to treat headaches can actually cause headaches. When pain medicines are taken daily on a regular schedule, missing one or two doses can result in a headache.

You also can develop a rebound headache if you decrease the amount of caffeine you use. For example, if you normally drink a lot of coffee, tea or energy drinks but don't get your usual amount, you may get a headache.

## Other facts about headaches

Although there are many other types of headaches, these are the most frequent. It is not unusual for someone to have two different types of headache. For certain headaches like migraine, a family history is common.

## Should I worry about having a headache?

Most headaches are not dangerous. In the first few days after a concussion or head injury, a person should see a health care professional experienced in treating persons with brain injuries IF the following occurs:

- Your headache gets worse.

- You have nausea and/or vomiting with a headache.
- You develop arm or leg weakness or problems speaking along with a headache.
- You have increasing sleepiness with headache.

## Do I need special tests to diagnose a headache?

In the first few days after a head injury, doctors will often order a CT scan of your brain to make sure there is no bleeding in your head. After that, a brain scan or other test is rarely needed in order to diagnose a headache accurately.

Usually, the health care provider will rely on your history and symptoms to sort out what kind of headache you are having and how to treat it.

## What can be used to treat a headache after TBI?

This will depend on each individual case. It's important to discuss your headaches with your doctor and to keep track of headaches and your response to treatment. Many people use a headache diary to help them do this.

## Lifestyle changes to help prevent headaches

The first steps in treating any type of headache don't involve drugs or other therapy. Many times, lifestyle factors can trigger headaches or make headaches worse. Making simple changes can often make a big difference in whether or not headaches occur. Try to:

- Get enough sleep.
- Get daily exercise. Aerobic exercise such as walking and good stretching often help to prevent headaches by improving sleep and decreasing triggers. If a headache is worsened by any particular exercise, check with your health care provider.
- Avoid caffeine.
- Avoid certain foods that may trigger a headache, like red wine, monosodium glutamate (MSG, a common food additive) or certain cheeses.

- Avoid taking pain medicines on a daily basis unless your health care provider prescribes it.

Common types of treatment for occasional headaches include:

- Over-the-counter pain medicines like acetaminophen (Tylenol®) or ibuprofen.
- Prescription medicines for migraine headache like sumatriptan (Imitrex®).
- Relaxation therapy/meditation.
- Biofeedback therapy.
- Stretching and self-massage.
- Acupuncture.
- Local injections (numbing medication or steroids, or for example) to muscles, nerves or joints of the cervical spine.
- Therapeutic massage.
- Heat or ice packs.

Treatments for recurrent headaches that happen more than twice a week

Headaches that occur frequently may require a prescription from your physician. The following medications may be used to treat headaches following TBI:

- Antidepressants.
- Antiseizure medicines (like gabapentin, also called Neurontin®).
- Certain blood pressure medication called beta-blockers (like propranolol).
- Botulinum toxin (Botox) injections.

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## Source

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## Authorship

# Returning to School after Traumatic Brain Injury

Parental involvement is critical when a young person is returning to school after a traumatic brain injury (TBI). Parents have the most knowledge about their child and are deeply invested in their daughter's or son's well-being and future. Often parents become advocates to ensure that all essential supports are in place to enhance their child's successful return to school. Parents may also be a go-between to make sure all the necessary medical information has been provided so the school can design the best plan for the student. If the student is close to exiting school, vocational rehabilitation professionals may also be involved.

## How does TBI affect students?

- The effects of TBI vary greatly from student to student; no two will be alike.
- Sometimes the effects of a brain injury are not obvious at first but become more noticeable later when thinking and social activities increase at school.

Some examples of changes that may occur after a person has sustained a TBI are:

- **Physical changes:** tiredness; lack of interest; headaches; awkward movements; slowed reactions; heightened sensitivity to light or noise.
- **Cognitive (thinking) changes:** forgetfulness; difficulty learning new material; word-finding difficulties; problems with organizing materials; easily distracted.
- **Emotional changes:** unable to deal with minor changes in the environment or daily routine; little or no expressed emotion; depression.
- **Behavioral changes:** irritability; inability to deal with unexpected event

## Planning to return to school

Much of the frustration and confusion related to returning to school can be avoided with proper planning. Rehabilitation professionals should communicate with family members and school personnel to help find the most effective ways to help the student return. This communication may need to be initiated by the student's family.

School personnel should be contacted as soon as possible after the injury to plan for the student's return to school. School personnel can also connect the student with services they need while they are not in school.

School systems are required to have special programs to help students with disabilities return to school. Most schools have trained special educators. However, not all special educators are familiar with the needs of students with brain injuries. On the other hand, not all students with TBI will require special programs.

In some states, a brain injury educational consultant is available through the state's Office of Special Education. This consultant helps special educators in local schools to assess and provide services to students with brain injuries.

Specific laws require schools to provide special services for students with disabilities:

- Individuals with Disabilities Education Improvement Act (IDEA) 2004 – These laws help ensure that students with disabilities receive a free appropriate education that is designed to meet their unique needs and prepare them for employment and independent living.
- Section 504 of the Rehabilitation Act – Some students who are not eligible for special education services under IDEA are eligible for other support at school under Section 504.
- American With Disabilities Act –These laws aim to end discrimination against individuals with disabilities throughout society.

For more information about these laws, parents can contact their local Department of Education or other resources listed at the end of this factsheet.

## How can schools support students with TBI?

It is important to obtain information about the student's pre-injury cognitive abilities from current or former teachers, and from the student's rehabilitation professionals such as neuropsychologists (psychologists who specializes in brain function), speech pathologists, occupational therapists, physical therapists and social workers.

Educators and family members need to understand the nature and severity of the injury. A neuropsychologist and other rehabilitation professionals can evaluate the student's current strengths and abilities and recommend possible

supports both in and out of the classroom. This information can be used to determine what classes the student should be placed in and any changes needed within the classroom.

Often a neuropsychological evaluation is used to answer questions such as:

- Can the student do the work needed to advance to the next grade or to participate in specific activities/classes (e.g. music class)?
- What are the student's cognitive strengths (e.g., ability to learn, memory for things to be done in the future, ability to plan and carry out events, ability to self-evaluate, initiative to start and finish tasks, and speed of thinking)?
- What are the student's social skills (e.g., emotional status, sensitivity, ability to handle stress)?
- What are the student's physical abilities, such as strength, balance and endurance?
- What are some of the problems the student may face, and what should educators look for?
- What classroom strategies can be used to help with attention, concentration, and learning (or other areas) for this student?

## What are possible classroom placement options?

There are basically four types of classroom placements.

- **Inclusion Class:** The student will be in a regular classroom. In addition to the teacher, a special education teacher will be available to adjust the curriculum to the student's abilities. While this arrangement allows the student to be in class with peers, it may not provide the intensive help some students need.
- **Resource Room:** Students who need intensive help to keep up with grade-level work in a particular subject may be placed in the Resource Room where a special-education teacher works with a small group of students. Resource Room placements have the benefit of providing help where needed while letting the student remain in regular classes most of the time.



- **Self-Contained Class:** Placement in a self-contained classroom means the student is taught in a small controlled setting with a special education teacher. Students in a self-contained class may be working at all different academic levels. The benefit is that the classes offer structure, routine and specialized instruction.
- **Out-of-District Placement:** Out-of-district placement requires the student to attend a specialized school specifically designed to address special learning or behavioral needs. The advantage is the high degree of specialized instruction. The disadvantage is the student does not attend the neighborhood school and misses peer interactions.

Every parent has a different opinion about placement. What is best will depend upon the student's needs.

The following questions may help parents and school staff to think through this important decision.

- What type of setting would most likely be the most conducive to learning?
- What are the disadvantages of not remaining in the regular classroom (loss of friendships, loss of confidence, etc?)
- What structure is needed?
- What specialized instructional techniques or technology are needed to enhance learning; where can these be provided without stigmatizing the student?
- Does the student need to focus on functional skills to enhance independent living and employment?
- Would the student benefit from learning "real" life or employment skills in setting outside of the classroom?
- Does the student plan to attend college?

Parents are advised to get input from others, including their child, teachers, other parents, special education personnel, and members of the

rehabilitation team. Once the student is placed it is important to monitor his or her progress so changes can be made as needed.

## Challenging behavior in the classroom

Several common "triggers" can cause or contribute to negative behaviors in the student with TBI.

- Students with TBI can become over-stimulated easily (from noisy hallways, crowded classes, too much information too quickly), which may lead to difficulty thinking and emotional distress.
- The student with TBI may respond negatively to an unexpected event or a lack of clear structure.
- Physical and cognitive activities at school may overwhelm the student to the point of an emotional outburst. Outbursts are more common as the student's level of fatigue increases throughout the day.
- Negative feedback and lack of support from teachers and other students, such as ridiculing or putting rigid demands on the student, can also contribute to emotional and behavioral problems.

## Ways educators can address challenging behavior

- Avoid labeling the student ("she hates math" or "he isn't motivated").
- First, talk to the student to find out what is contributing to the student's behavioral flare-ups. Is it emotional (e.g., poor self-esteem, depression), physical (e.g., headaches, fatigue), cognitive (e.g., poor memory, inattention) and/or lack of social skills?
- Evaluate the student's environment to determine what events may trigger behavioral problems. Also observe how the student interprets these events. The interaction of the events and the student's interpretation of the events may help in identifying the patterns of behavioral problems.

Behavior that is counterproductive in school does not “just emerge.” It follows a pattern, which may be complex but is, nevertheless, a pattern. The educator’s task is to detect and understand the pattern through discussions with the student, family and teachers, and observation in the classroom. Based on this understanding, changes can be made that minimize “triggers” of inappropriate behavior and support the student’s learning.

## Resources for Further Information

National Dissemination Center for Children with Disabilities.

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

National Association of Special Education Teachers.

[www.naset.org/traumaticbraininj2.0.html](http://www.naset.org/traumaticbraininj2.0.html)

Virginia Commonwealth University Rehabilitation and Research Training Center (VCURRTC) on Workplace Supports and Job Retention.

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

National Longitudinal Transition Study 2.

[www.nlts2.org/index.html](http://www.nlts2.org/index.html)

Pacer Center.

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

The National Center on Secondary Education and Transition.

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

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## Disclaimer

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## Source

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## Authorship

Returning to School after TBI was developed by Paul Wehman, PhD, and Pam Targett, M. Ed., in collaboration with the University of Washington Model Systems Knowledge Translation Center. Portions of this document were adapted from materials developed by Baylor Institute for Rehabilitation and Mayo Clinic TBI Model System.

# Seizures after Traumatic Brain Injury

One of the problems that can occur after a traumatic brain injury (TBI) is seizures. Although most people who have a brain injury will never have a seizure, it is good to understand what a seizure is and what to do if you have one. Most seizures happen in the first several days or weeks after a brain injury. Some may occur months or years after the injury. About 70-80% of people who have seizures are helped by medications and can return to most activities. Rarely, seizures can make you much worse or even cause death.

## What are seizures?

Seizures happen in 1 of every 10 people who have a TBI that required hospitalization. The seizure usually happens where there is a scar in the brain as a consequence of the injury.

During a seizure there is a sudden abnormal electrical disturbance in the brain that results in one or more of the following symptoms:

- Strange movement of your head, body, arms, legs, or eyes, such as stiffening or shaking.
- Unresponsiveness and staring.
- Chewing, lip smacking, or fumbling movements.
- Strange smell, sound, feeling, taste, or visual images.
- Sudden tiredness or dizziness.
- Not being able to speak or understand others.

Symptoms of a seizure happen suddenly, and you are unable to control them. Seizures usually last only a few seconds or minutes, but sometimes continue for 5 to 10 minutes. You may have a bladder or bowel accident or bite your tongue or the inside of your mouth during a seizure. After the seizure, you may be drowsy, weak, confused or have a hard time talking to or understanding others. After a severe seizure, one that lasts longer than 2 minutes, it may be harder for you to stand, walk or take care of yourself for a few days or even longer.

Conditions that could increase the risk of having a seizure include:

- High fever.
- Loss of sleep and extreme fatigue.
- Drug and alcohol use.
- Chemical changes in the body such as low sodium or magnesium, or high calcium.

## Seizures and TBI

- Early post-traumatic seizures: A seizure in the first week after a brain injury is called an early post-traumatic seizure. About 25% of people who have an early post-traumatic seizure will have another seizure months or years later.
- Late post-traumatic seizures: A seizure more than seven days after a brain injury is called a late post-traumatic seizure. About 80% of people who have a late post-traumatic seizure will have another seizure (epilepsy).
- Epilepsy: Having more than one seizure is called epilepsy. More than half the people with epilepsy will have this problem for their whole lives.

The cause of your brain injury can help doctors figure out how likely you are to have seizures.

- 65% of people with brain injuries caused by bullet wounds have seizures.
- 20% of people with 'closed head injuries' that cause bleeding between the brain and the skull experience seizures. A 'closed head injury' means the skull and brain contents were not penetrated in the injury.
- Over 35% of people who need 2 or more brain surgeries after a brain injury experience late post-traumatic seizures.
- Over 25% of people with bleeding on both sides of the brain, or who have a blood clot that must be removed by surgery, experience late post-traumatic seizures.

## Medications to treat seizures

Medications that are used to control seizures are called antiepileptic drugs (AEDs). These drugs may be used for other problems, such as chronic pain, restlessness, or mood instability. You and your doctor will decide on which drug to use based on your type of seizures, your age, how healthy you are, and if you get any side effects from the medications. Side effects of AEDs usually improve after you've been taking the medication for 3-5 days.

Some common side effects of AEDs are:

- Sleepiness or fatigue.
- Worsening of balance.
- Lightheadedness or dizziness.

- Trembling.
- Double vision.
- Confusion.

Blood tests may be needed to make sure you are getting enough of the medication and to make sure the drug isn't causing other problems. Although these drugs rarely cause birth defects in newborns, tell your doctor if you are pregnant or may become pregnant.

Sometimes your doctor will prescribe two or more of these medications to stop your seizures. Some common AEDs are:

- Carbamazepine (also known as Tegretol).
- Lamotrigine (also known as Lamictal).
- Levitiracetam (also known as Keppra).
- Gabapentin (also known as Neurontin).
- Oxcarbazepine (also known as Trileptal).
- Phenobarbital.
- Phenytoin/ fosphenytoin (also known as Dilantin).
- Pregabalin (also known as Lyrica).
- Topiramate (also known as Topamax).
- Valproic acid or valproate (also known as Depakene or Depakote).
- Zonisamide (also known as Zonegran).

## What if the medications do not work?

If your seizures continue even after trying medications, your doctor may refer you to a comprehensive Epilepsy Center for more tests and to be seen by special seizure doctors called epileptologists or neurologists specializing in epilepsy. At the comprehensive Epilepsy Center the doctors may do brain wave tests and take a video of you during one of your seizures to help figure out what is causing the problems. This may help your doctor decide what drug will work best, and to see if other types of treatment will help with the problems you are having.

The websites of the Epilepsy Foundation of America ([www.efa.org](http://www.efa.org)) or the American Epilepsy Society ([www.aesnet.org](http://www.aesnet.org)) can tell you about the nearest comprehensive Epilepsy Center.

## Safety Issues

In most states, if you have had a seizure you cannot drive and you must notify the department of motor vehicles (DMV). Usually you won't be able to return to driving for a period of time, or until your seizures have been completely stopped. Laws vary from state to state regarding how long after a seizure you must not drive.

Other things you should do to stay safe if your seizures have not stopped:

- Always have someone with you if you are in water (pool, lake, ocean, bath tub).
- Don't climb on ladders, trees, roofs or other tall objects.
- Let people you eat with know what to do in case you have a seizure and start choking.

## What your caregiver should do if you are having a seizure

Family members or caregivers should watch closely to see what happens during a seizure so they can explain it to medical professionals. They should make a diary describing the date, time of day, length of time, and description of each seizure. Your doctor will need this information about your seizures and the drugs you are taking to control them.

The majority of seizures are short and do not result in significant injuries. However, it is important for your caregivers to know what to do to keep you from hurting yourself.

What to do for someone having a seizure:

- Loosen tight clothing, especially around the neck.
- Make sure the person does not fall. Hold the person steady if he or she is in a chair, couch or bed. If the person is standing, get him or her to the ground safely.
- Turn the person and his or her head to the side so that anything in the mouth, even spit, does not block the throat.
- It can be dangerous to put anything in the mouth as you can get bitten.
- If you know CPR, check the heart beat in the neck. Start CPR if there is no pulse. Call 911.

- Listen for breathing at the mouth and extend the neck if breathing is difficult. If there is no breathing, start CPR by sealing your lips over the person's mouth and breathing 2 quick breaths. Continue breathing every 5 seconds unless the person starts breathing without help. Call 911.
- If this is the first seizure after TBI, call the person's doctor for advice.
- If the seizure does not stop after 3 minutes, call 911.
- If the seizure stops within 3 minutes, call the person's doctor.
- If the person does not return to normal within 20 minutes after the seizure, call 911.

## For More Information

The Epilepsy Foundation of America  
Phone: 1-800-332-1000

Web: [www.efa.org](http://www.efa.org)

Brain Injury Association of America  
Phone: 1-800-444-6443

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

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## Source

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## Authorship



# Sexuality after Traumatic Brain Injury

Changes in sexual functioning are common after TBI. If you are experiencing sexual problems, there are things you can do to help resolve these problems. The information below describes common sexual problems after TBI and ways to improve sexual functioning.

## How does a traumatic brain injury affect sexual functioning?

The following changes in sexual functioning can happen after TBI:

- *Decreased Desire:* Many people may have less desire or interest in sex.
- *Increased Desire:* Some people have increased interest in sex after TBI and may want to have sex more often than usual. Others may have difficulty controlling their sexual behavior. They may make sexual advances in inappropriate situations or make inappropriate sexual comments.
- *Decreased Arousal:* Many people have difficulty becoming sexually aroused. This means that they may be interested in sex, but their bodies do not respond. Men may have difficulty getting or keeping an erection. Women may have decreased vaginal lubrication (moisture in the vagina).
- *Difficulty or Inability to Reach Orgasm/Climax:* Both men and women may have difficulty reaching orgasm or climax. They may not feel physically satisfied after sexual activity.
- *Reproductive Changes:* Women may experience irregular menstrual cycles or periods. Sometimes, periods may not occur for weeks or months after injury. They may also have trouble getting pregnant. Men may have decreased sperm production and may have difficulty getting a woman pregnant.

## What causes changes in sexual functioning after TBI?

There are many reasons sexual problems happen after TBI. Some are directly related to damage to the brain. Others are related to physical problems or changes in thinking or relationships.

Possible causes of changes in sexual functioning after TBI include:

- *Damage to the Brain:* Changes in sexual functioning may be caused by damage to the parts of the brain that control sexual functioning.
- *Hormonal Changes:* Damage to the brain can affect the production of hormones, like testosterone, progesterone, and estrogen. These changes in hormones affect sexual functioning.



- *Medication Side Effects:* Many medications commonly used after TBI have negative side effects on sexual functioning.
- *Fatigue/Tiredness:* Many people with TBI tire very easily. Feeling tired, physically or mentally, can affect your interest in sex and your sexual activity.
- *Problems with Movement:* Spasticity (tightness of muscles), physical pain, weakness, slowed or uncoordinated movements, and balance problems may make it difficult to have sex.
- *Self-Esteem Problems:* Some people feel less confident about their attractiveness after TBI. This can affect their comfort with sexual activity.
- *Changes in Thinking Abilities:* Difficulty with attention, memory, communication, planning ahead, reasoning, and imagining can also affect sexual functioning.
- *Emotional Changes:* Individuals with TBI often feel sad, nervous, or irritable. These feelings may have a negative effect on their sexual functioning, especially their desire for sex.
- *Changes in Relationships and Social Activities:* Some people lose relationships after TBI or may have trouble meeting new people. This makes it difficult to find a sexual partner.
- Get a comprehensive medical exam. This should include blood work and maybe a urine screen. Make sure you discuss with your provider any role your medications may play. Women should get a gynecology exam and men may need a urology exam. Ask your doctor to check your hormone levels.
- Consider psychotherapy or counseling to help with emotional issues that can affect sexual functioning.
- Adjusting to life after a TBI often puts stress on your intimate relationship. If you and your partner are having problems with your relationship, consider marital or couples therapy.
- Consider starting sex therapy. A sex therapist is an expert who helps people to overcome sexual problems and improve sexual functioning. You can search for a certified sex therapist in your geographic area on the following web-site: <http://www.aasect.org/>
- Talk with your partner and plan sexual activities during the time of day when you are less tired.
- When having sex, position yourself so that you can move without being in pain or becoming off balance. This may mean having sex in a different way or unfamiliar position. Discuss this with your partner.
- Arrange things so that you will be less distracted during sex. For example, be in a quiet environment without background noise, such as television.

## What can be done to improve sexual functioning after TBI?

- Talk with your doctor, nurse practitioner, or other health or rehabilitation professional about the problem, so they can help you find solutions. Some people may feel embarrassed talking openly about sexual issues. It may help to keep in mind that sexuality is a normal part of human functioning, and problems with sexuality can be addressed just like any other medical problem. If you are not comfortable discussing sexual problems with your doctor, it is important to find a health professional who you do feel comfortable talking with.
- If you have trouble becoming sexually aroused, it may help to watch movies or read books/magazines with erotic images and other sexual content.
- There are sexual aids developed to help people with disability. A good website for these aids is: [www.Mypleasure.com/education/disability/index.asp](http://www.Mypleasure.com/education/disability/index.asp)
- Increasing your social network can increase the opportunity to form intimate relationships. You may consider joining a club or becoming involved in other social organizations.

## Importance of safe sex

After a TBI, it is just as important for you to protect yourself from unplanned pregnancy and from sexually transmitted disease as it was before your injury. Even if a woman's period has not returned, she can still get pregnant. Here are some tips to help with birth control and protection from sexually transmitted disease.

- Do research to help figure out what method of birth control and protection from sexually transmitted disease are best for you. The following website has some helpful information: <http://www.plannedparenthood.org>
- Because of changes in thinking abilities, it may be harder for you to remember to use protection or to remember to take it with you.
  - You can plan ahead by always carrying a condom or other method of protecting yourself and your partner.
  - For women who use birth control pills, or a device that must be replaced, using a calendar or alarm on a smart phone can help you remember to take the pills or change the device.
- If you are unsure whether your partner has a sexually transmitted disease or has been intimate with others who have such disease, it is safest to use a condom.
- If you have engaged in any risky sexual behavior, one of the best things you can do for yourself is to get tested for sexually transmitted diseases – and get treated if you test positive.

## Resources for further information

Sexuality Is A Family Matter by Carolyn Rocchio in Family News And Views: A Monthly Publication of the Brain Injury Association, 1993. <http://www.bianj.org/Websites/bianj/Images/Sexuality%20is%20a%20family%20matter.pdf>

Sexual Dysfunction Following Injury: Time for Enlightenment and Understanding: Suggestions by Center for Neuro Skills. <http://www.neuroskills.com/tbi/sex-suggestions.html>

Brain Trauma and Sexuality by Stanly Ducharme. [http://www.stanleyducharme.com/resources/combin\\_injury.htm](http://www.stanleyducharme.com/resources/combin_injury.htm)

Traumatic Brain Injury and Sexual Issues by Better Health Channel. [http://www.betterhealth.vic.gov.au/bhcv2bhcarticles.nsf/pages/Traumatic\\_brain\\_injury\\_and\\_sexual\\_issues](http://www.betterhealth.vic.gov.au/bhcv2bhcarticles.nsf/pages/Traumatic_brain_injury_and_sexual_issues)

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## Authorship

Sexuality after Traumatic Brain Injury was developed by Angelle M. Sander, Ph.D. and Kacey Maestas, Ph.D., in collaboration with the investigators of the TBI Model Systems Collaborative Project on Sexuality after TBI, and the University of Washington Model Systems Knowledge Translation Center. Portions of this document were adapted from Sexual Functioning and Satisfaction After Traumatic Brain Injury: An Educational Manual (authors: Sander AM, Moessner AN, Kendall, KS, Pappadia, MR, Hammond, FM, Cyborski CM).

# Sleep and Traumatic Brain Injury

## How common are sleep problems following a TBI?

Many people who have brain injuries suffer from sleep disturbances. Not sleeping well can increase or worsen depression, anxiety, fatigue, irritability, and one's sense of well-being. It can also lead to poor work performance and traffic or workplace accidents. A review of sleep disorder studies and surveys suggest that sleep disorders are three times more common in TBI patients than in the general population and that nearly 60% of people with TBI experience long-term difficulties with sleep. Women were more likely to be affected than men. Sleep problems are more likely to develop as the person ages.

## What are types of sleep problems?

Sleep disturbances have been found in people with all severities of brain injuries – from mild to severe. Sleep is a complex process that involves many parts of the brain. For this reason, and depending on the location and extent of injury, many different kinds of sleep disturbances can occur after brain injury.

## Common sleep disorders include:

- Insomnia: Difficulty with falling asleep or staying asleep; or sleep that does not make you feel rested. Insomnia can worsen other problems resulting from brain injury, including behavioral and cognitive (thinking) difficulties. Insomnia makes it harder to learn new things. Insomnia is typically worse directly after injury and often improves as time passes.
- Excessive Daytime Sleepiness: Extreme drowsiness.
- Delayed Sleep Phase Syndrome: Mixed-up sleep patterns.
- Narcolepsy: Falling asleep suddenly and uncontrollably during the day.

## Common sleep syndromes include:

- Restless Leg Syndrome (RLS): Urge to move the legs because they feel uncomfortable, especially at night or when lying down.
- Bruxism: Grinding or clenching teeth.
- Sleep Apnea: Brief pauses in breathing during sleep, resulting in reduced oxygen flow to the brain and causing loud snoring and frequent awakening.

- Periodic limb movement disorder (PLMD): Involuntary movement of legs and arms during sleep.
- Sleepwalking: Walking or performing other activities while sleeping and not being aware of it.

## What causes sleep problems?

The brain directs sleep by putting your body to rest. Injury to the brain can lead to changes in sleep.

### Physical and chemical changes

The “internal clock” in the brain controls when people sleep and wake every day. If injured, the brain may not be able to tell the body to fall asleep or wake up. There are chemicals in our body that help us to sleep. An injury can change the way that these chemicals affect the body. If brain mechanisms for starting and stopping sleep are injured, a condition called post-traumatic hypersomnia may result in which a person sleeps many hours more than normal.

### Changes in breathing control

Sometimes the brain’s ability to control breathing during sleep becomes altered after a TBI, resulting in periods of apnea (when breathing actually stops for long enough for blood oxygen levels to drop). This is called sleep apnea. Other factors may affect the chance of having sleep apnea such as family history or being overweight.

### Medications

Medications taken after a brain injury may cause problems going to sleep or staying asleep, or can make people sleepy during the day and unable to participate in activities.

- Prescription drugs for treating asthma and depression may cause insomnia. Also, stimulants that are meant to treat daytime sleepiness can cause insomnia if taken too close to bedtime. These problems can often be avoided by adjusting the timing of the medication or by substituting a different drug – of course, in consultation with your physician. Many other medications can cause sedation (sleepiness), as well.

- Most over-the-counter sleep aid medications contain an antihistamine (commonly diphenhydramine) and are not recommended for people with TBI because they may cause disturbances in memory and new learning. Retention of urine, dry mouth, nighttime falls and constipation are also possible side effects of this class of medications.

### Daytime sleeping (napping) and physical inactivity

Napping during the day is likely to disturb sleep at night. Inactivity or lack of exercise can also worsen sleep.

### Pain

Many people who have suffered brain injuries also experience pain in other parts of the body. This discomfort may disturb sleep. Medications taken to relieve pain may also affect sleep.

### Depression

Depression is much more common in persons with traumatic brain injury than in the general population. Sleep problems such as difficulty falling asleep and early morning waking are common symptoms of depression.

### Alcohol

While alcohol may help bring on sleep, drinking alcohol before bedtime is likely to interfere with normal sleep rather than improve it.

### Caffeine and Nicotine

Nicotine from tobacco may cause sleep disturbances and is often overlooked. Caffeine can disturb sleep when consumed in the afternoon or evening.

## What can be done to improve sleep?

Changes in behavior and environment are the first line to treating sleep difficulties.

### Daytime Suggestions

- Set an alarm to try to wake up at the same time every day.

- Include meaningful activities in your daily schedule.
- Get off the couch and limit TV watching.
- Exercise every day. People with TBI who exercise regularly report fewer sleep problems.
- Try to get outdoors for some sunlight during the daytime. If you live in an area with less sun in the wintertime, consider trying light box therapy.
- Don't nap more than 20 minutes during the day.

## Nighttime Suggestions

- Try to go to bed at the same time every night and set your alarm for the next day.
- Follow a bedtime routine. For example, put out your clothes for morning, brush your teeth and then read or listen to relaxing music for 10 minutes before turning out the light.
- Avoid caffeine, nicotine, alcohol and sugar for five hours before bedtime.
- Avoid eating prior to sleep to allow time to digest, but also do not go to bed hungry, as this can also wake you from sleep.
- Do not exercise within two hours of bedtime but stretching or meditation may help with sleep.
- Do not eat, read or watch TV while in bed.
- Keep stress out of the bedroom. For example, do not work or pay bills there.
- Create a restful atmosphere in the bedroom, protected from distractions, noise, extreme temperatures and light.
- If you don't fall asleep in 30 minutes, get out of bed and do something relaxing or boring until you feel sleepy.

## Talk to your doctor

If your sleep problems persist, talk to your doctor to explore safe and effective solutions. Evaluation of sleep problems should include a thorough history of such problems, medication review, an assessment of your bedtime routines, and a comprehensive medical evaluation. Before

recommending any action, your physician will explore with you a variety of possible causes for your sleep problems, including pain or depression. If necessary, he or she may recommend a polysomnographic evaluation (also known as a sleep lab). Based on your symptoms, medical history and specific needs, your doctor will be able to make a personalized treatment plan to help you achieve restful sleep.

## Treatment options

### Non-pharmacological therapies

- If mood or emotional issues such as anxiety or depression are causing sleep difficulties, psychotherapy (counseling) may be an appropriate treatment.
- Sleep restriction may improve sleeping patterns by restricting the number of hours spent in bed to the actual number of hours slept.
- For those with anxiety, relaxation therapy can help create a restful environment both in your bedroom and in your body and mind.
- Use of special bright lights (phototherapy) has been shown in studies to help promote sleep. When exposed to these lights at strategic times in the day, you may be able to sleep more at night. However, consult with your doctor first, as these bright lights can cause eyestrain and headaches.

### Medications

Ask your doctor about medications that can help you sleep through the night or keep you awake during the day. Special care is necessary when choosing a medication in order to avoid daytime sedation or worsening of cognitive and behavior problems.

### Natural remedies

Some consumers have found herbal teas, melatonin and valerian useful for sleep problems, and these are sold in health food and drug stores with no prescription needed. However, these remedies have multiple drug interactions, and you should tell your doctor if you are using them.

## Recommended readings and resources

- Brain Basics: Understanding Sleep – NINDS/NIH. [http://www.ninds.nih.gov/disorders/brain\\_basics/understanding\\_sleep.htm](http://www.ninds.nih.gov/disorders/brain_basics/understanding_sleep.htm)
- University of Maryland Sleep Hygiene: Helpful Hints to Help You Sleep. [http://www.umm.edu/sleep/sleep\\_hyg.htm](http://www.umm.edu/sleep/sleep_hyg.htm)
- [www.sleepnet.com](http://www.sleepnet.com)
- Thaxton, L., & Myers, M.A. (2002). Sleep disturbances and their management in patients with brain injury. *J Head Trauma Rehabil*, 17(4), 335-348.

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### Authorship

*Sleep and TBI* was developed by Brian Greenwald, MD and Kathleen Bell, MD in collaboration with the University of Washington Model Systems Knowledge Translation Center. Portions of this document were adapted from materials developed by the New York TBIMS, the Carolinas TBI Rehabilitation and Research System, and from *Picking up the pieces after TBI: A guide for Family Members*, by Angelle M. Sander, PhD, Baylor College of Medicine (2002).



# Understanding TBI

## Part 1: What happens to the brain during injury and in the early stages of recovery from TBI?

### What is a brain injury?

Traumatic brain injury (TBI) refers to damage to the brain caused by an external physical force such as a car accident, a gunshot wound to the head, or a fall. A TBI is not caused by something internal such as a stroke or tumor, and does not include damage to the brain due to prolonged lack of oxygen (anoxic brain injuries). It is possible to have a TBI and never lose consciousness. For example, someone with a penetrating gunshot wound to the head may not lose consciousness.

Commonly accepted criteria established by the TBI Model Systems (TBIMS)\* to identify the presence and severity of TBI include:

Damage to brain tissue caused by an external force and at least one of the following:

- A documented loss of consciousness
- The person cannot recall the actual traumatic event (amnesia)
- The person has a skull fracture, post-traumatic seizure, or an abnormal brain scan due to the trauma

### Causes of TBI

Statistics from Centers for Disease Control for 2002-2006 indicate that the leading cause of brain injury is falls (35%) followed by car crashes (17%) and being struck by an object (16%). Emergency room visits due to TBI caused by falls are increasing for both younger and older people. However, if you focus only on moderate to severe TBI (those injuries that require admission to a neurointensive care unit), car crashes are the most frequent cause of TBI, followed by gunshot wound, falls, and assault.

### Types of injuries

The brain is about 3–4 pounds of extremely delicate soft tissue floating in fluid within the skull. Under the skull there are three layers of membrane that cover and protect the brain. The brain tissue is soft and therefore can be compressed (squeezed), pulled, and stretched. When there is sudden speeding up and slowing down, such as in a car crash or fall, the brain can move around violently inside the skull, resulting in injury.

### Closed versus open head injury

*Closed* means the skull and brain contents have not been penetrated (broken into or through), whereas *open* means the skull and other protective layers are penetrated and exposed to air. A classic example of an open head injury

is a gunshot wound to the head. A classic closed head injury is one that occurs as the result of a motor vehicle crash.

In a **closed head injury**, damage occurs because of a blow to the person's head or having the head stop suddenly after moving at high speed. This causes the brain to move forward and back or from side to side, such that it collides with the bony skull around it. This jarring movement bruises brain tissue, damages axons (part of the nerve cell), and tears blood vessels. After a closed head injury, damage can occur in specific brain areas (localized injury) or throughout the brain (diffuse axonal injury).

Damage following **open head injury** tends to be localized and therefore damage tends to be limited to a specific area of the brain. However, such injuries can be as severe as closed head injuries, depending on the destructive path of the bullet or other invasive object within the brain.

## Primary versus secondary injuries

Primary injuries occur at the time of injury and there is nothing that physicians can do to reverse those injuries. Instead, the goal of the treatment team in the hospital is to prevent any further, or secondary, injury to the brain. Below are some primary injuries.

- **Skull fracture** occurs when there is a breaking or denting of the skull. Pieces of bone pressing on the brain can cause injury, often referred to as a depressed skull fracture.
- **Localized injury** means that a particular area of the brain is injured. Injuries can involve bruising (contusions) or bleeding (hemorrhages) on the surface of or within any layer of the brain.
- **Diffuse axonal Injury (DAI)** involves damage throughout the brain and loss of consciousness. DAI is a "stretching" injury to the neurons (the cell bodies of the brain) and axons (fibers that allow for communication from one neuron to another neuron). Everything our brains do for us depends on neurons communicating. When the brain is injured, axons can be pulled, stretched, and torn. If there is

too much injury to the axon, the neuron will not survive. In a DAI, this happens to neurons all over the brain. This type of damage is often difficult to detect with brain scans.

Secondary injuries occur after the initial injury, usually within a few days. Secondary injury may be caused by oxygen not reaching the brain, which can be the result of continued low blood pressure or increased intracranial pressure (pressure inside the skull) from brain tissue swelling.

## Measuring the severity of TBI

"Severity of injury" refers to the degree or extent of brain tissue damage. The degree of damage is estimated by measuring the duration of loss of consciousness, the depth of coma and level of amnesia (memory loss), and through brain scans.

The **Glasgow Coma Scale (GCS)** is used to measure the depth of coma. The GCS rates three aspects of functioning:

- Eye opening
- Movement
- Verbal response

Individuals in deep coma score very low on all these aspects of functioning, while those less severely injured or recovering from coma score higher.

- A GCS score of 3 indicates the deepest level of coma, describing a person who is totally unresponsive.
- A score of 9 or more indicates that the person is no longer in coma, but is not fully alert.
- The highest score (15) refers to a person who is fully conscious.

A person's first GCS score is often done at the roadside by the emergency response personnel. In many instances, moderately to severely injured people are intubated (a tube is placed down the throat and into the air passage into the lungs) at the scene of the injury to ensure the person gets enough oxygen. To do the intubation the person must be sedated (given medication that makes the person go to sleep). So, by the time

the person arrives at the hospital he/she has already received sedating medications and has a breathing tube in place. Under these conditions it is impossible for a person to talk, so the doctors cannot assess the verbal part of the GCS. People in this situation often receive a “T” after the GCS score, indicating that they were intubated when the examination took place, so you might see a score of 5T, for instance. The GCS is done at intervals in the neurointensive care unit to document a person’s recovery.

Post-traumatic amnesia (PTA) is another good estimate for severity of a brain injury. Anytime a person has a major blow to the head he or she will not remember the injury and related events for sometime afterward. People with these injuries might not recall having spoken to someone just a couple of hours ago and may repeat things they have already said. This is the period of post-traumatic amnesia. The longer the duration of amnesia, the more severe the brain damage.

## CT or MRI Scan Results

The cranial tomography (CT) scan is a type of X-ray that shows problems in the brain such as bruises, blood clots, and swelling. CT scans are not painful. People with moderate to severe TBI will have several CT scans while in the hospital to keep track of lesions (damaged areas in the brain). In some cases, a magnetic resonance imaging (MRI) scan may also be performed. This also creates a picture of the brain based on magnetic properties of molecules in tissue. Most people with severe TBI will have an abnormality on a CT scan or MRI scan. These scans cannot detect all types of brain injuries, so it is possible to have a severe TBI and be in coma even though the scan results are normal.

## Brain tissue response to injury

### Common Problems:

#### Increased intracranial pressure

The brain is like any other body tissue when it gets injured: it fills with fluid and swells. Because of the hard skull around it, however, the brain has nowhere to expand as it swells. This swelling

increases pressure inside the head (intracranial pressure), which can cause further injury to the brain. Decreasing and controlling intracranial pressure is a major focus of medical treatment early after a TBI. If intracranial pressure remains high, it can prevent blood passage to tissue, which results in further brain injury.

## Neurochemical problems that disrupt functioning

Our brains operate based on a delicate chemistry. Chemical substances in the brain called neurotransmitters are necessary for communication between neurons, the specialized cells within our central nervous system. When the brain is functioning normally, chemical signals are sent from neuron to neuron, and groups of neurons work together to perform functions.

TBI disturbs the delicate chemistry of the brain so that the neurons cannot function normally. This results in changes in thinking and behavior. It can take weeks and sometimes months for the brain to resolve the chemical imbalance that occurs with TBI. As the chemistry of the brain improves, so can the person’s ability to function. This is one reason that someone may make rapid progress in the first few weeks after an injury.

## Natural plasticity (ability of change) of the brain

The brain is a dynamic organ that has a natural ability to adapt and change with time. Even after it has been injured, the brain changes by setting up new connections between neurons that carry the messages within our brains. We now know the brain can create new neurons in some parts of the brain, although the extent and purpose of this is still uncertain.

Plasticity of the brain occurs at every stage of development throughout the life cycle. Plasticity is more likely to occur when there is stimulation of the neural system, meaning that the brain must be active to adapt. Changes do not occur without exposure to a stimulating environment that prompts the brain to work. These changes do not occur quickly. That is one of the reasons that recovery goes on for months and sometimes years following TBI.

Rehabilitation sets in motion the process of adaptation and change. Keep in mind that formal rehabilitation, such as received in a hospital from professional therapists, is a good initial step, but in most cases this must be followed by outpatient therapies and stimulating activities in the injured person's home.

## \*What is the TBIMS?

The TBIMS is a group of 16 medical centers funded by the National Institute on Disability and Rehabilitation Research (NIDRR). The TBIMS works to maintain and improve a cost-effective, comprehensive service delivery system for people who experience a TBI, from the moment of their injury and throughout their life span.

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## Authorship

## More in the Understanding TBI series

- Understanding TBI, Part 2: Brain injury impact on individuals' functioning
- Understanding TBI, Part 3: The recovery process
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# Understanding TBI

## Part 2: Brain injury impact on individuals' functioning

A traumatic brain injury interferes with the way the brain normally works. When nerve cells in the brain are damaged, they can no longer send information to each other in the normal way. This causes changes in the person's behavior and abilities. The injury may cause different problems, depending upon which parts of the brain were damaged most.

There are three general types of problems that can happen after TBI: physical, cognitive and emotional/ behavioral problems. It is impossible to tell early on which specific problems a person will have after a TBI. Problems typically improve as the person recovers, but this may take weeks or months. With some severe injuries changes can take many years.

### Structure and function of the brain

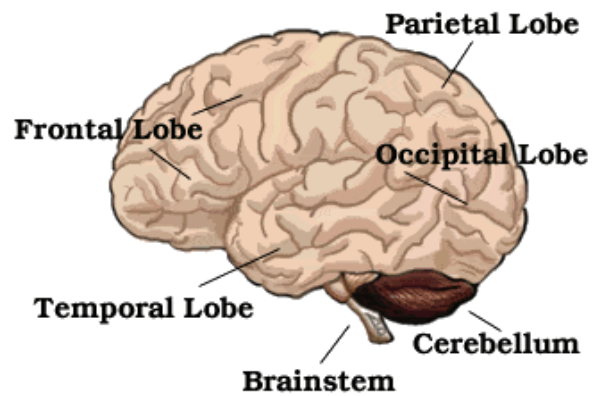
The brain is the control center for all human activity, including vital processes (breathing and moving) as well as thinking, judgment, and emotional reactions. Understanding how different parts of the brain work helps us understand how injury affects a person's abilities and behaviors.

### Left vs. Right Brain

- The brain is divided into two halves (hemispheres). The left half controls movement and sensation in the right side of the body, and the right half controls movement and sensation in the left side. Thus, damage to the right side of the brain may cause movement problems or weakness on the body's left side.
- For most people, the left half of the brain is responsible for verbal and logical functions including language (listening, reading, speaking, and writing), thought and memory involving words.
- The right half is responsible for nonverbal and intuitive functions such as putting bits of information together to make up an entire picture, recognizing oral and visual patterns and designs (music and art), and expressing and understanding emotions.

### Brain Areas & Associated Functions

The brain is made up of six parts that can be injured in a head injury. The effect of a brain injury is partially determined by the location of the injury. Sometimes only a single area is affected, but in most cases of TBI multiple areas have been injured. When all areas of the brain are affected, the injury can be very severe.



<b>Six parts</b>	<b>Functions</b>
Brain Stem	<ul style="list-style-type: none"> <li>▪ Breathing</li> <li>▪ Heart Rate</li> <li>▪ Swallowing</li> <li>▪ Reflexes for seeing and hearing</li> <li>▪ Controls sweating, blood pressure, digestion, temperature</li> <li>▪ Affects level of alertness</li> <li>▪ Ability to sleep</li> <li>▪ Sense of balance</li> </ul>
Cerebellum	<ul style="list-style-type: none"> <li>▪ Coordination of voluntary movement</li> <li>▪ Balance and equilibrium</li> <li>▪ Some memory for reflex motor acts</li> </ul>
Frontal Lobe	<ul style="list-style-type: none"> <li>▪ How we know what we are doing within our environment</li> <li>▪ How we initiate activity in response to our environment</li> <li>▪ Judgments we make about what occurs in our daily activities</li> <li>▪ Controls our emotional response</li> <li>▪ Controls our expressive language</li> <li>▪ Assigns meaning to the words we choose</li> <li>▪ Involves word associations</li> <li>▪ Memory for habits and motor activities</li> <li>▪ Flexibility of thought, planning and organizing</li> <li>▪ Understanding abstract concepts</li> <li>▪ Reasoning and problem solving</li> </ul>
Parietal Lobe	<ul style="list-style-type: none"> <li>▪ Visual attention</li> <li>▪ Touch perception</li> <li>▪ Goal directed voluntary movements</li> <li>▪ Manipulation of objects</li> <li>▪ Integration of different senses</li> </ul>
Occipital Lobes	<ul style="list-style-type: none"> <li>▪ Vision</li> </ul>
Temporal Lobes	<ul style="list-style-type: none"> <li>▪ Hearing ability</li> <li>▪ Memory acquisition</li> <li>▪ Some visual perceptions such as face recognition and object identification</li> <li>▪ Categorization of objects</li> <li>▪ Understanding or processing verbal information</li> <li>▪ Emotion</li> </ul>



## Physical Problems

Most people with TBI are able to walk and use their hands within 6-12 months after injury. In most cases, the physical difficulties do not prevent a return to independent living, including work and driving.

In the long term the TBI may reduce coordination or produce weakness and problems with balance. For example, a person with TBI may have difficulty playing sports as well as they did before the injury. They also may not be able to maintain activity for very long due to fatigue.

## Cognitive (Thinking) Problems

- Individuals with a moderate-to-severe brain injury often have problems in basic cognitive (thinking) skills such as paying attention, concentrating, and remembering new information and events.
- They may think slowly, speak slowly and solve problems slowly.
- They may become confused easily when normal routines are changed or when things become too noisy or hectic around them.
- They may stick to a task too long, being unable to switch to different task when having difficulties.
- On the other hand, they may jump at the first “solution” they see without thinking it through.
- They may have speech and language problems, such as trouble finding the right word or understanding others.
- After brain injury, a person may have trouble with all the complex cognitive activities necessary to be independent and competent in our complex world. The brain processes large amounts of complex information all the time that allows us to function independently in our daily lives. This activity is called “executive function” because it means “being the executive” or being in charge of one’s own life.

## Emotional/Behavioral Problems

Behavioral and emotional difficulties are common and can be the result of several causes:

- First, the changes can come directly from damage to brain tissue. This is especially true for injuries to the frontal lobe, which controls emotion and behavior.
- Second, cognitive problems may lead to emotional changes or make them worse. For example, a person who cannot pay attention well enough to follow a conversation may become very frustrated and upset in those situations.
- Third, it is understandable for people with TBI to have strong emotional reactions to the major life changes that are caused by the injury. For example, loss of job and income, changes in family roles, and needing supervision for the first time in one’s adult life can cause frustration and depression.

Brain injury can bring on disturbing new behaviors or change a person’s personality. This is very distressing to both the person with the TBI and the family. These behaviors may include:

- Restlessness
- Acting more dependent on others
- Emotional or mood swings
- Lack of motivation
- Irritability
- Aggression
- Lethargy (sluggishness)
- Acting inappropriately in different situations
- Lack of self-awareness. Injured individuals may be unaware that they have changed or have problems. This can be due to the brain damage itself or to a denial of what’s really going on in order to avoid fully facing the seriousness of their condition.

Fortunately, with rehabilitation training, therapy and other supports, the person can learn to manage these emotional and behavioral problems.

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# Understanding TBI

## Part 3: The Recovery Process

### Common stages

In the first few weeks after a brain injury, swelling, bleeding or changes in brain chemistry often affect the function of healthy brain tissue. The injured person's eyes may remain closed, and the person may not show signs of awareness. As swelling decreases and blood flow and brain chemistry improve, brain function usually improves. With time, the person's eyes may open, sleep-wake cycles may begin, and the injured person may follow commands, respond to family members, and speak. Some terms that might be used in these early stages of recovery are:

- **Coma:** The person is unconscious, does not respond to visual stimulation or sounds, and is unable to communicate or show emotional responses.
- **Vegetative State:** The person has sleep-wake cycles, and startles or briefly orients to visual stimulation and sounds.
- **Minimally Conscious State:** The person is partially conscious, knows where sounds and visual stimulation are coming from, reaches for objects, responds to commands now and then, can vocalize at times, and shows emotion<sup>1</sup>.

A period of confusion and disorientation often follows a TBI. A person's ability to pay attention and learn stops, and agitation, nervousness, restlessness or frustration may appear. Sleeping patterns may be disrupted. The person may overreact to stimulation and become physically aggressive. This stage can be disturbing for family because the person behaves so uncharacteristically.

Inconsistent behavior is also common. Some days are better than others. For example, a person may begin to follow a command (lift your leg, squeeze my finger) and then not do so again for a time. This stage of recovery may last days or even weeks for some. In this stage of recovery, try not to become anxious about inconsistent signs of progress. Ups and downs are normal.

Later stages of recovery can bring increased brain and physical function. The person's ability to respond may improve gradually.

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<sup>1</sup> Giacino, et al. The minimally conscious state: definition and diagnostic criteria. *Neurology*. 2002 Feb 12;58(3):349-53.

## Length of recovery

The fastest improvement happens in about the first six months after injury. During this time, the injured person will likely show many improvements and may seem to be steadily getting better. The person continues to improve between six months and two years after injury, but this varies for different people and may not happen as fast as the first six months. Improvements slow down substantially after two years but may still occur many years after injury. Most people continue to have some problems, although they may not be as bad as they were early after injury. Rate of improvement varies from person to person.

## Long-term impacts

It is common and understandable for family members to have many questions about the long-term effects of the brain injury on the injured person's ability to function in the future. Unfortunately, it is difficult to determine the long-term effects for many reasons.

- First, brain injury is a relatively new area of treatment and research. We have only begun to understand the long-term effects in patients one, five, and ten years after injury.
- Brain scans and other tests are not always able to show the extent of the injury, so it is sometimes difficult early on to fully understand how serious the injury is.
- The type of brain injury and extent of secondary problems such as brain swelling varies a great deal from person to person.
- Age and pre-injury abilities also affect how well a person will recover.

We do know that the more severe the injury the less likely the person will fully recover. The length of time a person remains in a coma and duration of loss of memory (amnesia) following the coma are useful in predicting how well a person will recover.

The Rancho Los Amigos Levels of Cognitive Functioning (RLCF) is one of the best and most widely used ways of describing recovery from

brain injury. The RLCF describes ten levels of cognitive (thinking) recovery. Research has shown that the speed at which a person progresses through the levels of the RLCF can predict how fully a person will recover.

## The Rancho Los Amigos Levels of Cognitive Functioning

Level 1 — No Response: Person appears to be in a deep sleep.

Level 2 — Generalized Response: Person reacts inconsistently and not directly in response to stimuli.

Level 3 — Localized Response: Person reacts inconsistently and directly to stimuli.

Level 4 — Confused/Agitated: Person is extremely agitated and confused.

Level 5 — Confused-Inappropriate/Non-agitated: Person is confused and responses to commands are inaccurate.

Level 6 — Confused-Appropriate: Person is confused and responds accurately to commands.

Level 7 — Automatic-Appropriate: Person can go through daily routine with minimal to no confusion.

Level 8 — Purposeful-Appropriate: Person has functioning memory, and is aware of and responsive to their environment.

Level 9 — Purposeful-Appropriate: Person can go through daily routine while aware of need for stand by assistance.

Level 10 — Purposeful-Appropriate/Modified Independent: Person can go through daily routine but may require more time or compensatory strategies.

## Recovery two years after brain injury

Based on information of people with moderate to severe TBI who received acute medical care and inpatient rehabilitation services at a TBI Model System, two years post-injury:

- Most people continue to show decreases in disability.
- 34% of people required some level of supervision during the day and/or night.
- 93% of people are living in a private residence.
- 34% are living with their spouse or significant other; 29% are living with their parents.
- 33% are employed; 29% are unemployed; 26% are retired due to any reason; and 3% are students.

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# Understanding TBI

## Part 4: The impact of a recent TBI on family members and what they can do to help with recovery

### How does brain injury affect family members?

For most family members, life is not the same after TBI. We want you to know that you are not alone in what you are feeling. While everyone's situation is a bit different, there are some common problems that many family members experience such as less time for yourself, financial difficulties, role changes of family members, problems with communication, and lack of support from other family members and friends. These are just some of the problems that family members may face after injury. Sometimes these problems can seem too much and you may become overwhelmed, not seeing any way out. Family members have commonly reported feeling sad, anxious, angry, guilty, and frustrated.

### Ways to reduce stress

Since the injury, you have likely been under a great deal of stress. A little stress is part of life, but stress that goes on for a long time can have a negative effect on the mind and body.

Stress is related to medical problems such as heart disease, cancer, and stroke.

- Stress can make you do things less well because it affects your ability to concentrate, to be organized, and to think clearly.
- Stress also has a negative effect on your relationships with other people because it makes you irritable, less patient, and more likely to lash out at others.
- Stress can lead to depression and/or anxiety.

If you are under constant stress, you are not going to be as helpful to your injured family member or anyone else. ***If you do not take the time to rest and care for yourself, you will get fewer things done, which will lead to more stress.*** If you won't do this for yourself, do it for your injured family member. They will be better off if you are healthy and rested. Here are some suggestions for ways to reduce stress and stay healthy. These things have worked for many people, but not all of them may work for you. The important thing is that you begin thinking about ways to improve your life.

### Learn to relax

Taking a few moments to relax can help you be more ready for the things you need to do. Learning to relax is not easy, especially in your current situation. There are relaxation techniques that can help you such as breathing



deeply and focusing on your breathing, stating a word or phrase that has positive meaning (e.g. peace), or visual imagery. In order to train your body and mind to relax, you need to practice often. Don't give up if it doesn't work right away. If you keep practicing these techniques, you will feel more relaxed in the long run, and you will find that you're able to function better in all areas of your life.

## Learn which coping strategies work for you

No matter what was going on in your life before, the injury has caused changes. You may never have experienced anything similar to the injury, and some of your usual coping strategies may not work in your current situation. The best thing that you can do for yourself is to be open to trying new ways of coping and find out what works for you.

Some coping strategies that others have found helpful:

- Taking time for yourself
- Keeping a regular schedule for yourself
- Getting regular exercise such as taking a 20-30 minute walk each day
- Participating in support groups
- Maintaining a sense of humor
- Being more assertive about getting the support you need
- Changing roles and responsibilities within the family

## Learn how to reward yourself

Everyone needs something to look forward to. You'll probably say, "I have no time; it's impossible." Just remember that you will be more ready to do the things you have to do if you take some time to do some things that you want to do. Even if you have very limited time, you can find some small way to reward yourself. Promise yourself a cup of your favorite coffee or an opportunity to watch a good TV show or read something you enjoy.

## Problem-solving for caregivers

Sometimes you may feel overwhelmed by problems. There may be so many problems that you're not sure which one to tackle first. You can only solve one problem at a time, so pick one. Use the problem solving steps below to find a good solution. Try to choose a smaller problem to solve first. This will give you practice and make you more confident about solving bigger problems. If you deal with problems in this way, they may seem easier to handle.

### Steps in Problem Solving

- I. *Identify the problem:* What is the problem? Define it as clearly and specifically as possible. Remember that you can only solve one problem at a time.
- II. *Brainstorm solutions:* What can be done? Think of as many things as you can. Don't worry about whether they sound silly or realistic. This is the time to think about all possibilities, even the ones that you don't think will happen. Be creative.
- III. *Evaluate the alternatives:* Now you will start thinking about the consequences of the ideas you came up with in Step 2. For each idea, make a list of positives on one side of the page and a list of negatives on the other side.
- IV. *Choose a solution:* Pick the solution with the best consequences based on your list of positives and negatives. Keep in mind that more positives than negatives is not always the best rule. Sometimes you will have one negative that outweighs many positives.
- V. *Try the solution:* Try out the idea you have chosen. Give it more than one chance to work. If it doesn't work right away, try to figure out why. Was there some consequence you didn't think of? Is there another problem in the way that could be easily solved?
- VI. *If your first solution doesn't work, try another one:* Don't give up. Everything doesn't always work out the first time. You can learn from your mistakes; they may help you to choose a better solution next time.

## Ways family members can help the injured person

The treatment team can provide you with guidance in how to help the person while not giving them too much or too little assistance. Attending therapy when possible and working with the therapists and nurses are the best ways to learn to help the person before discharge from the hospital.

The following recommendations are intended to help families and caregivers care for their loved one once they have returned home. Not all of the following recommendation may apply to your situation.

### Provide structure and normalcy to daily life

- Establish and maintain a daily routine - this helps the person feel more secure in their environment.
- Place objects the person needs within easy reach.
- Have the person rest frequently. Don't let the person get fatigued.
- Be natural with the person and help them to maintain their former status in the family. Communication is important to the person's recovery. Although they may not be able to speak, they should continue to be involved in as normal a social world as possible.
- Include the person in family activities and conversations.
- Keep a calendar of activities visible on the wall. Cross off days as they pass.
- Maintain a photo album with labeled pictures of family members, friends, and familiar places.

### Provide support in a respectful way

- Try not to overwhelm the person with false optimism by saying statements like "You will be alright" or "You will be back to work in no time."

- Point out every gain the person has made since the onset of the injury. Avoid comparing speech, language or physical abilities prior to the injury with how they are now. Look ahead and help the person to do the same.
- Treat the person as an adult by not talking down to them.
- Respect the person's likes and dislikes regarding food, dress, entertainment, music, etc.
- Avoid making the person feel guilty for mistakes and accidents such as spilling something.
- If the person has memory problems, explain an activity as simply as possible before you begin. Then as you do the activity, review with the person each step in more detail.

**Avoid over-stimulation** - Agitation can be heightened by too much activity and stimulation.

- Restrict the number of visitors (1 or 2 at a time).
- Not more than one person should speak at a time.
- Use short sentences and simple words.
- Present only one thought or command at a time and provide extra response time.
- Use a calm, soft voice when speaking with the person.
- Keep stimulation to one sense (hearing, visual or touch) at a time.
- Avoid crowded places such as shopping malls and stadiums.

### Safety Tips

The person who has confusion or impaired judgment may be unable to remember where dangers lie or to judge what is dangerous (stairs, stoves, medications). Fatigue and inability to make the body do what one wants can lead to injury. Therefore it is very important that a brain injured person live in an environment that has been made as safe as possible. The following are some safety guidelines to use in the home:

- Keep clutter out of the hallway and off stairs or anywhere the person is likely to walk. Remove small rugs that could cause tripping or falls.
- Remove breakables and dangerous objects (matches, knives, and guns).
- Keep medications in a locked cabinet or drawer.
- Get the doctor's consent before giving the person over-the-counter medication.
- Limit access to potentially dangerous areas (bathrooms, basement) by locking doors if the person tends to wander. Have the person wear an identification bracelet in case he or she wanders outside.
- Keep the person's bed low. If they fall out of the bed, you may want to place the mattress on the floor or install side rails.
- Make sure rooms are well lit, especially in the evening. Night-lights can help prevent falls.
- Have someone stay with the person who is severely confused or agitated.
- Keep exit doors locked. Consider some type of exit alarm, such as a bell attached to the door.
- Consider a mat alarm under a bedside rug to alert others if the person gets up during the night.

*Things that can be more dangerous after a TBI and should be resumed only after consulting a health care professional: contact sports, horseback riding, swimming, hunting or access to firearms, power tools or sharp objects, riding recreational vehicles, and cooking without supervision.*

Individuals with brain injury should receive permission from a health care professional prior to using alcohol or other substances at any point after their injury. Also, NO DRIVING until approved by your doctor.

## More in the Understanding TBI series

- Understanding TBI, Part 1: What happens to the brain during injury and in early stage of recovery from TBI?
- Understanding TBI, Part 2: Brain injury impact on individuals' functioning
- Understanding TBI, Part 3: The recovery process

## Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

## Source

Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the TBI Model Systems directors.

## Authorship

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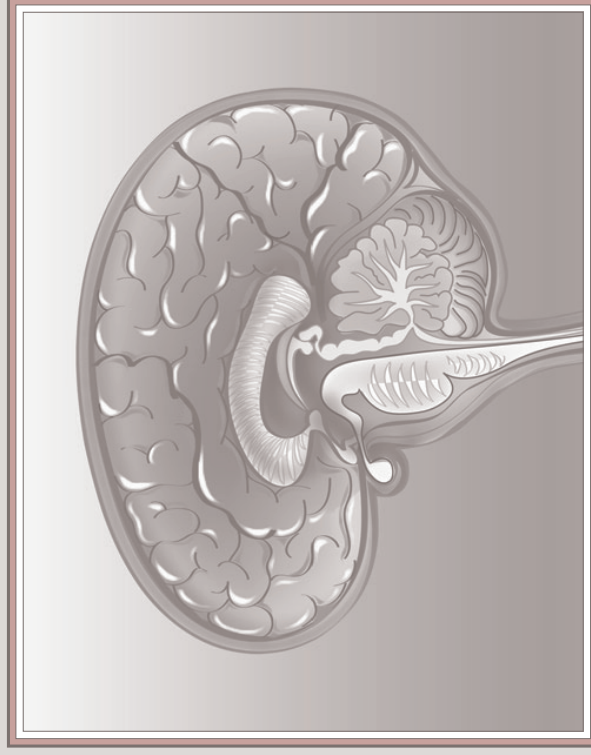
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# *Facts about the Vegetative and Minimally Conscious States after Severe Brain Injury*



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**Brain Injury  
Association  
of America**

**S**EVERE BRAIN INJURY causes a change in consciousness. Consciousness refers to awareness of the self and the environment. Brain injury can cause a wide range of disturbances of consciousness. Some injuries are mild and may cause relatively minor changes in consciousness such as brief confusion or disorientation.

The most severe injuries cause profound disturbance of consciousness. Twenty to 40% of persons with injuries this severe do not survive. Some persons who survive have a period of time of complete unconsciousness with no awareness of themselves or the world around them. The diagnosis given these people depends on whether their eyes are always closed or whether they have periods when their eyes are open. The state of complete unconsciousness with no eye opening is called **coma**. The state of complete unconsciousness with some eye opening and periods of wakefulness and sleep is called the **vegetative state**. As people recover from severe brain injury, they usually pass through various phases of recovery. Recovery can stop at any one of these phases.

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#### Characteristics of coma

1. No eye-opening
2. Unable to follow instructions





3. No speech or other forms of communication
4. No purposeful movement

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**Characteristics of the vegetative state**

1. Return of a sleep-wake cycle with periods of eye opening and eye closing
2. May moan or make other sounds especially when tight muscles are stretched
3. May cry or smile or make other facial expressions without apparent cause
4. May briefly move eyes toward persons or objects
5. May react to a loud sound with a startle
6. Unable to follow instructions
7. No speech or other forms of communication
8. No purposeful movement

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**Persons in coma or vegetative state require extensive care that may include:**

1. Feeding using a feeding tube
2. Turning in bed to prevent pressure sores
3. Special bedding to help prevent pressure sores
4. Assistance with bowel and bladder relief using catheter and/or diapers

5. Management of breathing such as suctioning of secretions; this may include care for a tracheostomy tube
6. Management of muscle tone (excessive tightness of muscles)
7. Special equipment that may include a wheelchair or special bedding to help with proper posture and decrease muscle tightness
8. Management of infections such as pneumonia or urinary tract infections
9. Management of other medical issues such as fever, seizures, etc.

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**What happens after coma and vegetative state?**

When people start to regain consciousness, they may:

1. follow simple instructions from others such as, “Open your eyes,” “Squeeze my hand,” “Say your name,” etc.;
2. communicate by speaking words or by indicating yes or no by head nods or gestures; and/or
3. use a common object in a normal way such as brushing hair with a brush, using a straw to drink, holding a phone to the ear, etc.



Persons with brain injury transition through the period of unconsciousness and subsequent stages of recovery at a slower or faster rate, largely depending on the severity of injury. Those with less severe injuries may transition through these stages more

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**As people recover from severe brain injury, they usually pass through various phases.**

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rapidly and some of the stages described here may be poorly recognized or not occur at all. Those with very severe injuries may stall at one or another stage and not be able to make the transition to a higher level of recovery.

For persons with more prolonged periods of unconsciousness, emergence from unconsciousness is a gradual process. Coma rarely lasts more than 4 weeks. Some patients move from coma to the vegetative state but others may move from coma to a period of partial consciousness. It would be very rare for a person to move directly from coma, or vegetative state, to a state of full consciousness.

Persons who have shorter periods of unconsciousness likely had less severe brain injuries initially. Consequently, they are likely to go on to make better recoveries than persons who had longer periods of unconsciousness.

Traumatic brain injury refers to damage to the brain caused by external force such as a car crash or a

fall. About 50% of persons who are in a vegetative state one month after traumatic brain injury eventually recover consciousness. They are likely to have a slow course of recovery and usually have some ongoing cognitive and physical impairments and disabilities. People in a vegetative state due to stroke, loss of oxygen to the brain (anoxia) or some types of severe medical illness may not recover as well as those with traumatic brain injury. Those few persons who remain in a prolonged vegetative state may survive for an extended period of time but they often experience medical complications such as pneumonia, respiratory failure, infections, etc. which may reduce life expectancy.

People who have a slow recovery of consciousness continue to have a reduced level of self-awareness or awareness of the world around them. They have inconsistent and limited ability to respond and communicate. This condition of limited awareness is called the **minimally conscious state**.

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**Characteristics of the minimally conscious state**

1. Sometimes follows simple instructions
2. May communicate yes or no by talking or gesturing
3. May speak some understandable words or phrases

4. May respond to people, things, or other events by:

- crying, smiling, or laughing;
- making sounds or gesturing;
- reaching for objects;
- trying to hold or use an object or
- keeping the eyes focused on people or things for a sustained period of time whether they are moving or staying still

People in a minimally conscious state do these things inconsistently. For example, one time the person might be able to follow a simple instruction and another time they might not be able to follow any instructions at all. This makes it difficult to distinguish the vegetative state from the minimally conscious state.

While in a minimally conscious state, people need extensive care similar to that needed by people in a vegetative state.

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**Emergence from the minimally conscious state**

Once a person can communicate, follow instructions, or use an object such as a comb or pencil consistently, they are no longer in a minimally conscious state. Some people remain minimally conscious indefinitely, but many improve. The longer a person remains in a minimally conscious

**Comparison of Coma, Vegetative State, and Minimally Conscious State**

	Coma	Vegetative State	Minimally Conscious State
Eye Opening	No	Yes	Yes
Sleep/Wake Cycles	No	Yes	Yes
Visual Tracking	No	No	Often
Object Recognition	No	No	Inconsistent
Command Following	No	No	Inconsistent
Communication	No	No	Inconsistent
Contingent Emotion	No	No	Inconsistent

state, the more permanent impairments he or she is likely to have. This is because vegetative and minimally conscious states are caused by severe damage to multiple brain areas. Following emergence from the minimally conscious state, people almost always experience confusion. Sometimes people move directly from coma to this confusional state.

**Characteristics of the confusional state**

1. Disorientation (inability to keep track of the correct date and place)
2. Severe impairment in attention, memory and other mental abilities

3. Fluctuation in level of responsiveness
4. Restlessness
5. Nighttime sleep disturbance
6. Excessive drowsiness and sleeping during the day
7. Delusions or hallucinations

As with the vegetative and minimally conscious states, the rate and extent of recovery from the confused state vary from person to person. However, almost all people who reach the confused state go on to make further progress. The main factors that

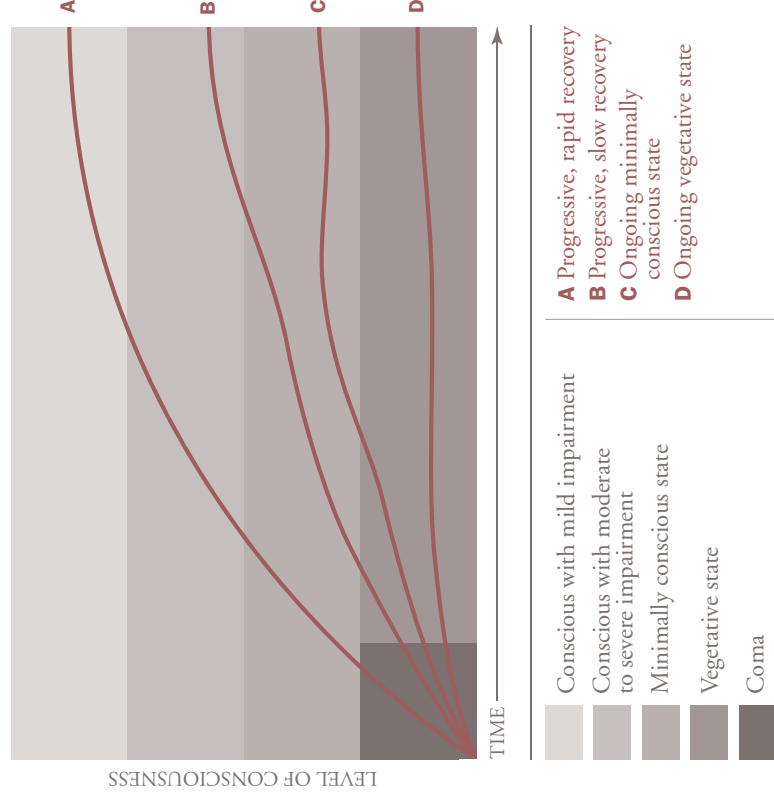
determine the eventual degree of recovery are the initial severity of the brain injury and some types of additional medical problems. The shorter the time the person is in the confused state, the better the eventual recovery will be. Mild medical complications such as sleep disturbance or urinary tract infection may prolong the confused state but do not necessarily influence the final outcome.

Once the confusional state resolves, people are usually much better able to pay attention, orient themselves to place and time, and retain memories for day to day experiences. Nevertheless, they are very likely to have some significant cognitive problems such as impaired memory or slowed thinking. These cognitive problems are likely to continue to

improve as time passes. Some people make limited progress, while others make a good deal of progress.

### Patterns of recovery after very severe brain injury

This image shows some patterns of recovery that follow emergence from coma. Some individuals rapidly emerge from coma and briefly remain in the minimally conscious state before recovering a higher level of consciousness with mild impairments. Others may have a longer period in the minimally



conscious state after emerging from the vegetative state and then usually have a greater degree of long-term impairment. Occasionally, persons remain in the vegetative or minimally conscious state for an extended period of time and, in rare cases, these conditions may be permanent.

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**What treatments are used with people in the vegetative or minimally conscious state?**

Currently, there is no treatment that has been proven to speed up or improve recovery from the vegetative or minimally conscious state. However, there is general agreement that the primary focus of medical care is to prevent or treat any factors that might hinder recovery (such as hydrocephalus, a

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**Persons who have shorter periods of unconsciousness likely had less severe brain injuries initially.**

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(such as treating infections or stiffness of joints). Medical facilities and clinicians vary in the extent to which they try various treatments such as medications or sensory stimulation to promote recovery of consciousness. Because the amount of recovery from disorders of consciousness varies so greatly, it is difficult to judge the value of these and other treatments outside of research studies. You can

inquire about your physician or program's philosophy about using these types of treatments.

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**Transitions to different levels of care**

At various points in the process of recovery, persons in the minimally conscious or vegetative state may receive care in a wide range of settings. Initially, the person with severely impaired consciousness is most likely to be treated in an acute care hospital where the focus is primarily on saving his/her life and stabilizing him/her medically. Once that is achieved, the next focus is on recovery of function to whatever level is possible. Sometimes this happens in an acute rehabilitation hospital, which provides a high intensity program of rehabilitation services, including physical therapy, occupational therapy, speech and language therapy, recreational therapy, neuropsychological services and medical services.

Some patients do not transition from the acute care hospital to an acute rehabilitation program. These people may go directly to a skilled nursing facility, a sub-acute rehabilitation program, a nursing home, or even home with family. Persons discharged from an acute rehabilitation program usually go to one of these places as well. Skilled nursing facilities, sub-acute rehabilitation programs, and nursing

homes vary widely in the quantity and quality of medical management, nursing care, and rehabilitation therapy services they provide.

**M**ANY FACTORS INFLUENCE DECISIONS about where a person with severe impairment of consciousness or other severe impairments may go after discharge from the acute care hospital or discharge from the acute rehabilitation program. Some of these factors are the person's medical condition, health insurance coverage and other benefits, the person's ability to tolerate rehabilitation therapies, the doctor's philosophy about where people should go to continue to recover after severe injuries, the family's ability to care for the person at home, the family's wishes, and practical matters such as that the distance the family has to travel to visit the person at the facility.

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**It is helpful to work with a social worker or case manager in the facility where your loved one is currently receiving services**

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The names used to describe levels of care and the settings in which they are provided, vary across the country. It is helpful to work with a social worker or case manager in the facility where your loved one is currently receiving services to plan whatever transitions are necessary. Do not be afraid to ask

questions to make sure that you obtain the information you need to help you make the best possible decision.

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**Things to look for when considering a setting to care for your loved one:**

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At various points in the process of recovery, persons in the minimally conscious or vegetative state may receive care in a wide range of settings. These include in-patient rehabilitation facilities, skilled nursing facilities, and long-term acute care facilities. The following are some considerations for selecting a place for care:

1. Your family member's current treatment team has had good experiences with the program when they have referred others there.
2. The staff at the facility makes you feel comfortable, is accessible to talk with about your concerns, and answers your questions.
3. The program and medical staff have experience working with the same kinds of problems that your family member has.
4. The facility is informed about the specifics of the care your loved one needs and is able to meet these care needs. You can have a role in ensuring that a detailed nursing plan of care is developed.



5. The program includes case management to assist in planning for the next level of service, whether it is transition to a rehabilitation program, a facility for long-term care, or home.
6. The program provides education and training for future caregivers.
7. The program uses specific procedures to measure progress.  
If support services can be arranged, some persons in the minimally conscious or vegetative state can be cared for at home.

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#### **Thoughts from families who have been there**

Family members who have a loved one in a minimally conscious or vegetative state have identified a number of important issues:

1. *Communicating with healthcare providers*  
Be sure to ask questions, share your observations, and express your opinions.
2. *Managing medical equipment and supplies*  
It is important to be knowledgeable about your loved one's equipment and supplies, and know how to communicate with the companies who provide these items.
3. *Providing care*  
Family members often provide some of the care

for their loved ones. The amount of care you provide will depend on your role in providing care (this can range from providing most of the care yourself to simply directing the care provided by others), the people such as sitters, attendants, nurses, and family members who are available to help you with providing care, the setting (this could be your home or a skilled nursing facility), and the guidance you receive from health care providers. It is desirable to obtain as much training as possible to provide whatever elements of care you chose to provide and are able to manage. These might include bathing, grooming, bowel and bladder management, mobility, range of motion, and other medical issues that your loved one may have.

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#### **If support services can be arranged, some persons in the minimally conscious or vegetative state can be cared for at home.**

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#### 4. *Learning about financial resources*

You may initially feel overwhelmed when you start to learn about various financial resources that may be appropriate for your loved one. However, with patience, persistence, and some help from others, you will be able to figure out which programs apply and find your way through the application processes.



Programs you will want to learn about include:

- Healthcare programs such as Medicare and Medicaid.
- Income replacement or financial assistance programs such as SSDI (Social Security Disability Insurance), SSI (Supplemental Security Income), or possibly disability insurance policies that you loved one may have had through work.
- Services to help with community living such as state agencies that assist people in these areas.

It might not be possible to find someone who knows everything about how to access these various services and programs. The key is to

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**The most natural way of interacting is to talk to your loved one, even though he or she may not respond or understand.**

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may be helpful to you are social workers, therapists, case managers, the local social security office, your state brain injury association chapter, family members or friends who are disabled or who have family who are disabled, or the human resources (personnel) department at your loved one's employer.

## 5. *Guardianship*

Since your loved one is not able to fully make decisions for himself or herself, it may be helpful for you, or someone else, to be appointed guardian. This may make it easier to handle medical decision making or management of your loved one's financial matters. If you think that your loved one may need to have a guardian appointed, you will need to contact an attorney to get assistance. Guardianship can be reversed when it is no longer needed.

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**How to interact with your loved one who is unconsciousness or at a low level of responsiveness**

The most natural way of interacting is to talk to your loved one, even though he or she may not respond or understand. Simple things like telling him or her about recent events in your life, what is going on in your family or neighborhood, or the latest news might make you feel a sense of connection. Talking with your loved one about what you are doing as you provide care can increase your comfort with the process of care giving. For example, telling your loved one that you are going to move his or her arms and legs to help prevent joint tightness might make you feel more comfortable with this task. Only do this "range of motion" type

activity if you have been instructed to do so by the doctor, nurse, or therapist.

Physical touch is another way of having a sense of connection. Some family members have said that the act of giving a massage or applying lotion to the hands or face helps them to feel close to their loved one. It is also important to avoid the risk of overstimulation as this may result in rapid breathing, tightening of the muscles, grinding of the teeth, restlessness and fatigue.

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### **Taking care of yourself and other family members**

Family members of a person in a vegetative or minimally conscious state often feel a sense of loss or grief for the relationship they had prior to the injury. There can be a number of ways to cope with these feelings. A person in a minimally conscious or vegetative state may make very slow progress or go for periods of time with no apparent progress. Sometimes keeping a journal of the changes you have observed may be comforting. This may give you a chance to look back and see ways in which he or she is more able to respond than he or she was at an earlier point in time.

Having a loved one who is in a vegetative or minimally conscious state can be physically and emotionally draining. Managing this alone can be

too much to ask of one person. It is important to rely on support from others, looking to existing supports and developing new ones. You might find help from supports you have relied on in the past, such as family, friends, and religious groups.



OTHER RESOURCES TO CONSIDER include support groups, support agencies, and the Internet. A good way to learn more about these possible supports is to make a contact with the Brain Injury Association of America's National Brain Injury Information Center ([www.biausa.org](http://www.biausa.org), 1-800-444-6443) and obtain contact information for the closest state brain injury association (BIAA) chapter. Health care providers such as doctors, therapists, social workers and others can be good sources of information about supports available to you.

Even the most committed caregiver needs to have some private time. If your loved one is at home, this can range from having a friend or family member give you a 2 hour break to go do something for yourself to having full time caregivers for a week or having your loved one spend a brief time in a nursing care facility or hospital. If your loved one is still in the hospital or living in a nursing care facility, having a rotating visitation schedule can give you some breaks while giving other friends and family a chance to spend time with him or her.

When your loved one was first injured you were likely to be in crisis mode, focusing on the problems and putting the rest of life on hold. As time goes by, you will need to shift from crisis management mode, and begin to take care of the concerns of everyday life such as paying bills, maintaining relationships with other family members, and taking care of your own physical and mental health. While it is natural to focus on your injured loved one, other members of your family will have needs too. For some people, formal counseling with a therapist or member of the clergy can be an important part of making adjustments to life changes that have occurred as a result of your loved one's injury.

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**Even the most committed caregiver needs to have some private time.**

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While caring for a person in a vegetative or minimally conscious state is an enormous challenge, use of appropriate resources, as described above, can be a big help. Each person will respond differently to this challenge, but almost everyone can cope and move forward. Many family members have a deep sense of personal satisfaction in making life as comfortable and pleasant as possible for a loved one who has sustained a severe injury.

While caring for a person in a vegetative or minimally conscious state is an enormous challenge, use of appropriate resources, as described above, can be a big help. Each person will respond differently to this challenge, but almost everyone can cope and move forward. Many family members have a deep sense of personal satisfaction in making life as comfortable and pleasant as possible for a loved one who has sustained a severe injury.







